# UNMET HEALTH CARE SERVICE NEEDS AND CAREGIVER NEEDS OF CHILDREN WITH DISABILITIES IN PENANG, MALAYSIA.

TAN SEOK HONG

THESIS SUBMITTED IN FULFILMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PUBLIC HEALTH

FACULTY OF MEDICINE
UNIVERSITY OF MALAYA
KUALA LUMPUR

2016

**UNIVERSITY OF MALAYA**

**ORIGINAL LITERARY WORK DECLARATION**

Name of Candidate: Tan Seok Hong (I.C/Passport No: 781120-07-5360)

Registration/Matric No: MHC 110019

Name of Degree: Doctor of Public Health

Title of Project Paper/Research Report/Dissertation/Thesis ("this Work"):

Unmet Health Care Service Needs and Caregiver Needs of Children with Disabilities in Penang, Malaysia.

Field of Study: Public Health

I do solemnly and sincerely declare that:

(1) I am the sole author/writer of this Work;
(2) This Work is original;
(3) Any use of any work in which copyright exists was done by way of fair dealing and for permitted purposes and any excerpt or extract from, or reference to or reproduction of any copyright work has been disclosed expressly and sufficiently and the title of the Work and its authorship have been acknowledged in this Work;
(4) I do not have any actual knowledge nor do I ought reasonably to know that the making of this work constitutes an infringement of any copyright work;
(5) I hereby assign all and every rights in the copyright to this Work to the University of Malaya ("UM"), who henceforth shall be owner of the copyright in this Work and that any reproduction or use in any form or by any means whatsoever is prohibited without the written consent of UM having been first had and obtained;
(6) I am fully aware that if in the course of making this Work I have infringed any copyright whether intentionally or otherwise, I may be subject to legal action or any other action as may be determined by UM.

Candidate's Signature Date:

Subscribed and solemnly declared before,

Witness's Signature Date:

Name:

Designation:

## ABSTRACT

Unmet need for health services captures the degree to which needed health services are not received and is an indication of the difficulties experienced in the process of obtaining care. It is used to assess equity of access to health care across population subgroups. This study investigates whether current services are meeting the needs of children with disabilities and their caregivers in Penang, a state in Northern Malaysia. The objectives are to determine the magnitude of unmet service needs, as well as the child and family characteristics associated with these unmet needs. Problems faced by caregivers in getting access to needed services are identified. A cross-sectional population survey was conducted among caregivers of children with disabilities aged 0 – 12 years registered with the Penang Department of Social Welfare in 2012. Caregivers answered a self-administered mailed questionnaire which included an assessment of the child's unmet need for 17 specific medical services and assistive devices, and a newly developed 20-item Caregiver Needs Scale (CNS). A total of 305 questionnaires were available for analysis (response rate 37.9%). Among the respondents, 41.3% had children with learning disability, 27.5% with multiple disabilities and 31.2% with sole visual, hearing, or physical disability. Distribution of total number of unmet needs revealed that 23.5% did not have any unmet needs and 76.5% had one or more unmet needs. More than 50% of children had unmet needs for dietary advice, psychology services, dental services, speech therapy, home nursing services, communication aids, home modifications, mobility aids and vision aids. Children with multiple disabilities, of younger age, with more severe disability and caregivers with higher education reported more needs. However, school age children were more likely to have higher level of unmet needs and having more than one disabled child was associated with less unmet needs. Level of unmet needs was not associated with severity of disability, ethnicity, education level and income level. Even though the result did not reach

statistical significance, children with learning disability showed a tendency to have higher unmet needs compared to children with multiple disabilities. Overall, difficulties accessing services were mainly due to logistic problems, followed by issues related to skills and resources. Parent-provider relationship problems were least encountered. Caregivers needed the most help getting information and services for their child, followed by help with finances, help coping with the child, and lastly help getting child care. Caregivers of younger children and with more severe disability had more needs in all these domains. Besides that, caregivers of children with learning disability needed more help getting information and help with coping. Both caregivers of children with learning and multiple disabilities needed more help getting child care. Caregivers of Indian ethnicity, who had less than a tertiary education and who themselves had medical problems needed more help with finances. This study highlights the areas to prioritize in the provision and development of health services for children with disabilities in Malaysia, including support services for their families.

## ABSTRAK

Keadaan di mana sesuatu perkhidmatan kesihatan diperlukan tetapi tidak diterima oleh orang yang memerlukannya menunjukkan bahawa terdapat kesukaran dalam mendapatkan perkhidmatan tersebut. Perkara ini digunakan untuk menilai akses kepada perkhidmatan kesihatan di kalangan kumpulan tertentu dalam masyarakat. Kajian ini melihat samada perkhidmatan yang sedia ada memenuhi keperluan kanak-kanak kurang upaya dan penjaga mereka di negeri Pulau Pinang, di Malaysia Utara. Objektif kajian ini adalah untuk menentukan setakat mana keperluan perkhidmatan yang tidak dipenuhi, serta ciri-ciri kanak-kanak dan keluarga yang berkaitan. Masalah yang dihadapi oleh penjaga dalam mendapatkan perkhidmatan yang diperlukan juga dikenalpasti. Satu kaji selidik populasi dijalankan di kalangan penjaga kanak-kanak kurang upaya berumur 0 – 12 tahun yang berdaftar dengan Jabatan Kebajikan Masyarakat Pulau Pinang pada tahun 2012. Para penjaga menjawab satu soal selidik yang dihantar melalui pos, bagi menilai keperluan dan penerimaan 17 jenis perkhidmatan kesihatan dan peralatan perubatan, serta menjawab satu Skala Keperluan Penjaga. Sejumlah 305 soal selidik dianalisa (kadar respon 37.9%). Di kalangan responden, 41.3% mempunyai anak dengan masalah pembelajaran, 27.5% dengan pelbagai ketidakupayaan dan 31.2% kurang upaya penglihatan, pendengaran atau fizikal. Sebanyak 23.5% tidak mempunyai apa-apa keperluan perkhidmatan yang tidak dipenuhi manakala 76.5% mempunyai satu atau lebih keperluan perkhidmatan yang tidak dipenuhi. Lebih daripada 50% kanak-kanak tidak memperolehi nasihat pemakanan, perkhidmatan psikologi, pergigian, terapi pertuturan, penjagaan di rumah, alat bantuan komunikasi, pengubahsuaian di rumah, alat bantuan pergerakan dan alat penglihatan sepenuhnya. Kanak-kanak dengan pelbagai kurang upaya, yang lebih muda, dengan ketidakupayaan yang lebih teruk dan penjaga dengan tahap pendidikan lebih tinggi melaporkan lebih banyak keperluan. Namun begitu, kanak-kanak dalam umur persekolahan mempunyai lebih banyak keperluan yang

tidak dipenuhi manakala keluarga yang mempunyai lebih daripada seorang anak kurang upaya lebih mudah mendapatkan perkhidmatan. Tahap ketidakupayaan, kumpulan etnik, tahap pendidikan dan pendapatan didapati tidak berkaitan dengan keperluan yang tidak dipenuhi. Kanak-kanak dengan masalah pembelajaran cenderung mempunyai keperluan yang tidak dipenuhi berbanding kanak-kanak dengan pelbagai ketidakupayaan, walaupun keputusannya tidak signifikan dari segi statistik. Pada keseluruhannya, kesukaran mendapatkan perkhidmatan disebabkan oleh masalah logistik, diikuti masalah berkaitan sumber dan kemahiran. Kesukaran yang disebabkan oleh masalah hubungan pesakit dengan staf perkhidmatan paling kurang dihadapi. Penjaga memerlukan bantuan mendapatkan maklumat dan perkhidmatan untuk anak mereka, diikuti bantuan kewangan, bantuan menguruskan anak mereka, dan akhirnya bantuan mendapatkan khidmat jagaan. Penjaga kepada anak kecil dan anak dengan ketidakupayaan yang lebih teruk mempunyai lebih banyak keperluan dalam semua domain. Penjaga kepada kanak-kanak dengan masalah pembelajaran memerlukan lebih banyak maklumat dan bantuan menguruskan anak mereka. Kedua-dua penjaga kanak-kanak dengan masalah pembelajaran dan pelbagai ketidakupayaan memerlukan lebih banyak bantuan mendapatkan khidmat jagaan. Penjaga kaum India, penjaga yang mempunyai tahap pendidikan kurang daripada pengajian tinggi, dan penjaga yang dirinya sendiri mengalami masalah perubatan, memerlukan lebih banyak bantuan kewangan. Kajian ini membawa perhatian kepada bidang dan kumpulan yang perlu diberi penekanan dalam perkembangan perkhidmatan kesihatan untuk kanak-kanak kurang upaya di Malaysia, termasuk perkhidmatan sokongan untuk keluarga mereka.

## ACKNOWLEDGEMENTS

I would like to thank my supervisor, Associate Professor Wong Yut Lin, and my statistics lecturer, Associate Professor Karuthan Chinna, from the Department of Social and Preventive Medicine, University Malaya, Kuala Lumpur, Malaysia for their guidance and encouragement. My utmost gratitude to Dr Nik Daliana Nik Farid, who was brought on board at a later stage to become my co-supervisor, but who has been very helpful in her comments on this thesis.

I would also like to thank the following people for their invaluable input and assistance: Dr Aminah Bee Mohd Kassim and Dr Salimah Othman (Senior Principal Assistant Directors, Persons with Disabilities Health Unit of Family Health Development Division, Ministry of Health), Assoc. Prof. Mary Marret (Community Paediatrician and lecturer in University Malaya Medical Centre), Dato' Dr Amar Singh (Consultant Community Paediatrician Hospital Ipoh, Perak), Dr Angeline Yeoh (Head of Paediatric Department, Hospital Seberang Jaya), Dr Toh Teck Hock (Senior Paediatrician Hospital Sibu), Dr Chin Saw Sian (Paediatrician Borneo Medical Centre), Dr Rokiah Mohd (Senior Assistant Principal Director, Family Health Development Unit in the Penang State Health Department), Dr Tan Liok Ee (President of Bureau of Learning Difficulties Penang) and Ms Khor Ai Na, CEO of Asia Community Service Penang), and officers from the Department of Social Welfare, Penang.

This work is dedicated in the loving memory of my late father, who passed away during the final stages of writing up this thesis. Last but not least, thank you to the rest of my family members, who have been very supportive throughout the whole process.

## TABLE OF CONTENTS

**CHAPTER 2: LITERATURE REVIEW 29**

## LIST OF FIGURES

## LIST OF TABLES

## LIST OF SYMBOLS AND ABBREVIATIONS

| | | |
|---|---|---|
| CBR | : | Community Based Rehabilitation |
| CI | : | Confidence Interval |
| CNS | : | Caregiver Needs Scale |
| CSHCN | : | Children with Special Health Care Needs |
| CWD | : | Children with Disabilities |
| CWSN | : | Children with Special needs |
| DSW | : | Department of Social Welfare |
| FNS | : | Family Needs Survey |
| FSS | : | Family Support Scale |
| MDT | : | Multidisciplinary team |
| MOE | : | Ministry of Education |
| MOH | : | Ministry of Health |
| NGO | : | Non-governmental organization |
| NHMS | : | National Health and Morbidity Survey |
| OOP | : | Out of Pocket |
| OR | : | Odds Ratio |
| PWD | : | Persons with Disabilities |
| RM | : | Ringgit Malaysia |
| WHO | : | World Health Organization |

## LIST OF APPENDICES

# CHAPTER 1: INTRODUCTION

## 1.1 Introduction

Children with disabilities are one of the most vulnerable groups in society. There has been relative neglect of the issue of developmental delays and disabilities among children, especially in low and middle income countries (Maulik & Darmstadt, 2007). Understanding the experiences of these children and that of their families can help inform policies to improve their health outcomes.

The Convention on the Rights of the Child 2006 upholds the rights of the child with disability to receive education, training, health care and rehabilitation services, recreational opportunities and preparation for employment in a manner conducive to the child achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. Children and their families must have potential access to care, be able to use care appropriately and receive care that is of high quality.

Unmet needs are an indication of access problems to health care services. Margaret Whitehead (1991) defines inequity in health as differences which are unnecessary and avoidable, unjust and unfair. If we extrapolate this, inequitable access to health care becomes the differences in *access* which are unnecessary and avoidable, unjust and unfair. If a child with disability needs a certain service but does not receive it, this is referred to as an "unmet need". In order to develop effective and equitable models of care for children with disabilities, it is important to consider their unique needs and factors which predispose to their unmet needs.

This chapter introduces the research topic on children with disabilities, starting off with a background on disability, both internationally and in Malaysia. An overview of the policy and programmes for children with disabilities in Malaysia is given, including an explanation on the roles of different stakeholders or service providers. Systems, policies and programmes indirectly impact individual and family-level supports, services and practices. Lastly, the meaning of quality of life for people with disability and the rationale of doing the study is presented.

## 1.2 Definition of disability

Disability has often been defined as a physical, mental, or psychological condition that limits a person's activities (Mont, 2007). In the past, disability was linked to various medical diagnoses, and was seen solely as the result of an individual's inability to function. The medical model of interpreting disability has recently been replaced by the social model, which conceptualizes disability as arising from the interaction of a person's functional status with physical, cultural, and policy environments. If the environment is designed for the full range of human functioning and incorporates appropriate accommodations and supports, then people with functional limitations would not be "disabled" in the sense that they would be able to fully participate in society.

In 2001, the World Health Assembly endorsed the use of the International Classification of Functioning, Disability and Health (ICF) model to conceptualise and classify disability. In the ICF model, people are not identified as having a disability based on a medical condition, but rather are classified according to a detailed description of their functioning within various domains – *body structure and function*, *activities* and *participation* (WHO, 2001).

The *body structure and function* domain in the ICF is the most closely related to the earlier medical model. Body structures are defined as "anatomic parts of the body such as organs, limbs and their components." This domain relates to very specific capabilities, for example being able to lift one's arm over one's head or to produce articulate speech sounds. The *activities* and *participation* domains give a more 'whole person' classification. Activities are basic deliberate actions undertaken in order to accomplish a task, such as getting dressed or feeding oneself. Participation refers to activities that are integral to economic and social life and the social roles that accomplish that life, such as being able to attend school or to hold a job. Moreover, the ICF incorporates the social model by including information on how a person's ability to function is affected by the environment they encounter.

Malaysia's definition of persons with disabilities reflects the latest global thinking on disability, and mirrors that of the Convention on the Rights of Persons with Disabilities ("Laws of Malaysia: Persons with Disabilities Act," 2008). Persons with disabilities are defined as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN, 2006).

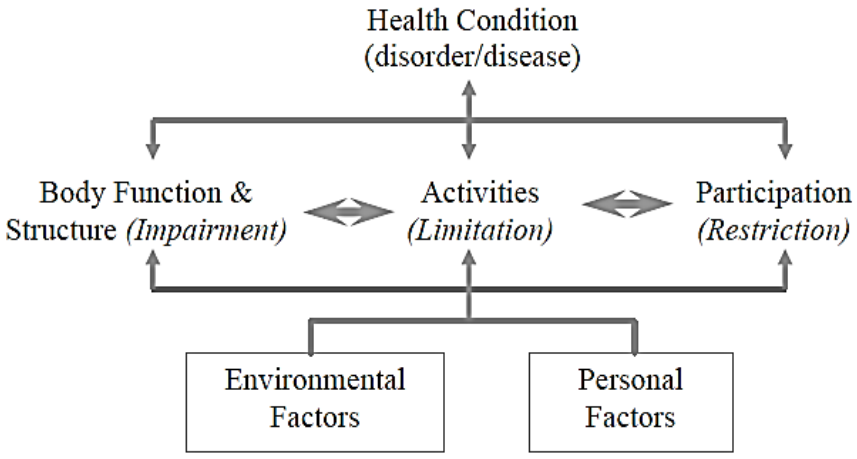


**Figure 1.1:** The ICF model of conceptualizing disability

For purposes of registration, persons with disabilities (PWDs) in Malaysia are categorised into certain types of disability. In June 2009, the categories were revised and now, PWDs are distinguished into visual, hearing, physical, learning, speech, mental and multiple disabilities categories (Department of Social Welfare, 2009a).

Those categorized under physical disability are persons with hemiplegia, paraplegia, tetraplegia, loss of limb or muscular weakness that causes them to have difficulty performing basic activities such as self-care and movement. The condition could be a result of trauma or malfunctions in the neurological, cardiovascular, respiratory, haematology, immunology, urology, hepatobiliary, musculoskeletal, gynaecology and other systems.

Those with learning disabilities are persons whose mental abilities are not congruent with their biological age. Persons in this category include those with global developmental delay, and those with intellectual disabilities, for example, Down syndrome. This category also includes individuals with conditions that impair their learning such as autism, attention deficit hyperactive disorder (ADHD) and specific learning disorders such as dyslexia, dyscalculia and dysgraphia.

Persons who had more than one disability and with conditions generally not suitable to be classified in any of the other six categories are classified under multiple disabilities.

### 1.3 Prevalence of disability

Disability is a phenomenon that is neither uniformly nor normally distributed across the total population. Because disability arises out of a complex model, it is often difficult to be captured in a single measure.

The different approaches taken in generating prevalence estimates of disability include (i) *self-identification* of the respondent as being disabled; (ii) asking about *diagnosable conditions* such as polio and paralysis; (iii) asking the respondents if they have difficulty in performing *activities of daily living* (ADL) which are task based and focus on basic activities such as dressing, bathing and feeding oneself; (iv) asking about *instrumental activities of daily living* (IADL) which are higher order tasks such as problems managing money and shopping for groceries and; (v) asking about *participation*, that is whether the person has some condition which affects a particular social role, such as attending school or being employed (WHO, 2001).

The Disability and Development Team of the World Bank in their "Measuring Disability Prevalence" paper states that reported disability prevalence rates from around the world vary dramatically, from under 1% in Kenya and Bangladesh to 20% in New Zealand (Mont, 2007). Data from developed countries and some recent studies in developing countries over several regions namely, Brazil, Ecuador, India, Nicaragua, Vietnam, and Zambia, suggest that the prevalence estimate of disability is 10 - 12%. The Asia and Pacific region is home to two thirds of the 650 million persons with disabilities in the world (ESCAP, 2010). In 31 Asia Pacific countries where data on prevalence of disability was available, the prevalence varies from 0.7 to 20%.

This variation is caused by several factors: differing definitions of disability, different methodologies of data collection, and variation in the quality of study design. Different countries use a different set of functional domains or a different severity threshold for

classifying people as being disabled. The result is that disability prevalence rates that are understandable and internationally comparable are unavailable.

This situation is complicated further by the idea that there is no single correct definition of disability, that the nature and severity of disabilities vary greatly, and that how one measures disability differs depending on the purpose for measuring it.

### 1.3.1 Prevalence of disability and results of disability surveys in Malaysia

In Malaysia, the total number of registered persons with disabilities (PWD) including both children and adults, in 2009 was 283,512 and in 2011 was 359,203 (Department of Social Welfare, 2009b). This is 1.0% and 1.2% of the total Malaysian population in those years respectively. PWD as a percentage of the population in the respective states and federal territories in 2009 ranged from 0.5 – 2.0%.

In 2011, the number of registered PWDs by ethnicity comprised of 62.6% Malays, 19.6% Chinese, 10.2% Indians, 7.0% ethnic natives and 0.6% other ethnicities. By type of disability, 8.9% had visual disability, 12.2% had hearing disability, 34.4% had physical disability, 37.5% had learning disability, 0.2% had speech disability, 2.5% had mental disability and 4.4% had other/multiple disabilities. It must be stated however that the date presented is cumulative and there may be misclassification due to changes in the categories of disability for purpose of registration in 2009. Number of PWDs by state and federal territory in 2011 is shown in table 1.1.

**Table 1.1:** No. of registered PWD in Malaysia by state and federal territory in 2011

| States/Federal territories | New cases | Total no. of cases |
|---|---|---|
| Selangor | 5951 | 51238 |
| Johor | 6199 | 43610 |
| Perak | 3304 | 34630 |
| Kelantan | 4057 | 31611 |
| K. Lumpur | 2534 | 25940 |
| Kedah | 1988 | 26829 |
| Pulau Pinang | 2352 | 23183 |
| Terengganu | 2457 | 21398 |
| Sabah | 2529 | 19936 |
| N. Sembilan | 2329 | 18172 |
| Sarawak | 2662 | 18036 |
| Melaka | 2451 | 18325 |
| Pahang | 5440 | 19822 |
| Perlis | 616 | 5587 |
| Labuan | 87 | 886 |
| **Total** | **44 956** | **359 203** |

By the end of 2012, the Department of Social Welfare (DSW) national registration system had 445,006 registered persons with disabilities, representing 1.5% of the country's mid-year population estimate of 29.52 million in that year. This total number is not disaggregated by age since statistics prior to 2011 did not capture this information. As such, it is not possible to tell how many out of this total number are children.

Only data on persons with disabilities who have registered from 2010 onwards can be disaggregated by age. In 2011, 15,263 out of 44,956 new registrations were children with disabilities. In 2012, 29,289 out of 85,803 new registrations were children with disabilities. The percentage of children registered in 2011 and 2012 was approximately

34% of total new registrations. Out of this, males made up 65.2% of new child registrations in 2011, and 61.6% in 2012.

According to the National Health and Morbidity Survey II (1996), the prevalence of physical disability was 3.2 per 1000 population and in the NHMS III (2006), this figure increased to 6.3 per 1000 population (NIH, 2006a). People were classified as physically disabled based on screening questions identifying physical impairments.

In the NHMS III, only 44% of the expected number of physically disabled persons was registered. Almost one third of individuals with physical disability are from households living below the poverty line of income less than RM700/month. This cut-off point is an average estimate of RM661 for Peninsular Malaysia, RM888 for Sabah and RM765 for Sarawak, according to the Ninth Malaysia Plan 2006 – 2010. The survey did not find any difference in the prevalence of physical disability among urban-rural distribution and ethnicity.

The NHMS III also found that 59% of persons with physical disability have never participated in any rehabilitation programme. The main reason quoted was lack of awareness of rehabilitative services. Other reasons were 'no need for rehabilitation' (24%), 'no one to send' (13%), 'no time to go for rehabilitation' (8%), 'financial problem' (4.5%) and 'no transport' (1%).

Prevalence of physical disability in children aged between 7 – 18 years was 2.8 per 1000 population. Out of this, one third of physically disabled children did not register with the Department of Social Welfare.

The impact of physical disability on children was examined in the areas of functional independence, schooling and access to public places. Slightly more than one third of children with physical disability aged 7 – 18 years old were partially or totally dependent on their caregivers. Those with more severe disability were found to have

more problems with functional independence and community participation. These school aged children were found to rely heavily on their caregivers for their mobility, whereby 68% of those who needed help for their mobility were carried around and only one of them (6.5%) used a wheelchair.

It was found that 25.5% of these children used gestures to communicate and 13.9% did not communicate at all, but none of them used any communication aids. Only 68.5% of the school aged children attended formal education. However the survey did not determine the reason behind the non-attendance; whether it was due to associated intellectual disability or behavioural problems, or due to societal or environmental limitations such as absence of a wheelchair-friendly school.

In addition, these children with physical disability were twice less likely to be taken to public places compared to those without physical disability, although the result was not statistically significant. Most of the children who were housebound were those with four limb involvement. Lack of transport was given as a reason in 34.4%.

The NHMS III also screened for psychiatric morbidity in children and adolescents, using a 10 item Reporting Questionnaire for Children (RQC) developed earlier by a team of WHO experts (NIH, 2006b). The questionnaire was used to screen children aged 5 to less than 16 years old. From the RQC, 8.6% of respondents answered that their child appeared backward or slow to learn, while 8.25% and 24.95% indicated that their child may have problem with inattention and hyperactivity respectively. However, the RQC is only a screening instrument and children were suspected but could not be confirmed to have learning difficulties.

### 1.4 Overview of policy and programmes for children with disabilities

Many developed countries have a disability act which provides for the rights and needs of people with disability, including the right to access high quality services. The rights of carers or families to receive supports are also included in some of the legal frameworks (Disability Law Service UK, 2009).

Community based rehabilitation (CBR) was recommended by the World Health Organization in 1989 as the strategy to improve the quality of life of disabled people and their families. The CBR model rejects the institutional care model and supports the maintenance of persons with disabilities within their homes and communities (Lysack & Kaufert, 1994). Although this model is used in countries all over the world, it is particularly responsive to the circumstances in developing countries where services for people with disability are extremely limited or even absent.

This paradigm shift in the care of children with disabilities from the institution to the home has resulted in a shift in the responsibility of care from the state to the family (Peter et al., 2007; Goddard, Davidson, Daly & Mackey, 2008). The political will and ideologies of different countries mean that the burden of care can be more pronounced in one party than the other.

In countries where the emphasis is on freedom of personal choice and individual rights, the responsibility of care falls primarily on the individual and his/her family, giving rise to the belief that families should meet their own needs. In these countries, the jurisdiction of services for children with disabilities is dispersed across numerous programmes and authorities with no single structure for policy implementation and accountability. By comparison, in countries where health and welfare are deemed a social responsibility, the state/government pays more attention to making sure community resources are provided for families of children with disabilities.

Services for children with disabilities typically need to be publicly funded, either fully or partially. Public funds may come from general taxation or social health insurance. In countries where health and welfare are deemed a social responsibility, the state/government tends to fund a large portion of services for children with disabilities, although the agencies providing these services may not be government owned.

Mechanisms for assessment and management of children with disabilities differ in different countries, but most involve child disability teams and early intervention or rehabilitation centres (Hendriks, Moor, Oud & Franken, 2000; Kovanen, 2001; King et al., 2002; Thyen, Sperner, Morfeld, Meyer & Ravens-Sieberer, 2003; Clark & MacArthur, 2008; Poon, Ooi, Bull & Bailey Jr, 2014).

### 1.4.1 Legal and policy framework in Malaysia

Malaysia ratified the Convention on the Rights of the Child (CRC) in 1995 and the Convention on the Rights of Persons with Disabilities (CRPD) in 2010, albeit with reservations to certain articles in both (UNICEF, 2014).

The CRC provides a binding implementation framework with implications for law, policy and practice with respect to children with disabilities. It requires State parties to recognise the rights of the child with disability to special care, and to render assistance free of charge to the child whenever possible. The CRPD addresses the rights of children with disabilities to participation, information, education, family life and freedom from violence.

Malaysia is also signatory to the Biwako Millennium Framework for Action (BMF) and its follow-up, the Biwako Plus Five under the Asia Pacific decade of persons with disabilities 2003 - 2012. The BMF and Biwako Plus Five are initiatives adopted by

governments in the Asia Pacific region to promote an inclusive, barrier-free and rights-based society for persons with disabilities.

In 2012, Malaysia together with other members of the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) adopted the Incheon Strategy under the third Asia Pacific decade of persons with disabilities 2013 – 2022 to "Make the Right Real" for persons with disabilities in Asia and the Pacific. The Incheon strategy is the first set of regionally agreed disability-inclusive development goals, building on the CRPD, the BMF and the Biwako Plus Five. Among others, it includes strategies for expanding early intervention of children with disabilities, strengthening social protection and enhancing accessibility to the physical environment, public transportation, knowledge, information and communication.

In Malaysia, the Child Act 2001, the Persons with Disabilities Act 2008 and the National Policy for PWD 2007 give recognition to the rights of children with disabilities to care, protection and development. All the rights and protections available to children under the Child Act extend to children with disabilities, including the right to life, survival and development, non-discrimination and serving the best interest of the child.

The Persons with Disabilities (PWD) Act provides for the registration, protection, rehabilitation, development and wellbeing of persons with disabilities, the establishment of the National Council for PWDs, and for matters connected therewith ("Laws of Malaysia: Persons with Disabilities Act," 2008). Chapter 2 of Part IV of the Act is concerned with the habilitation and rehabilitation of PWDs, including having in-home, residential and other community support services. Chapter 3 is concerned with access to health, prevention of further occurrence of disabilities and the availability of health personnel.

The National Policy for PWD 2007 acknowledges the rights of persons with disabilities to full participation in the Malaysian society and to equal opportunities and access under the relevant laws. This policy outlines 28 strategies encompassing 15 areas, namely advocacy, accessibility, health, rehabilitation, education, employment, personal safety and social security, support services, social, human resource development, community involvement, research and development, housing, women with disabilities and children with disabilities.

There is no national policy specifically for children with disabilities and an absence of an integrated national policy that cuts across service sectors. Policies at a ministerial level are framed for persons with disabilities as a whole, or for children as a whole. Goals and strategies for the care, protection and development of children with disabilities filter down from these policies (UNICEF, 2014).

Although the PWD Act and the National Policy for PWD have been criticized for not being specific and lacking commitment for practical implementation (UNICEF, 2014), they remain important frameworks for guiding programmes and services for people with disabilities in Malaysia.

### 1.4.2 Ministry of Health programmes and services

In 1996, Ministry of Health had already developed the National Health Programme and Plan of Action for the Health Care of PWDs. In view of recent international and regional developments, this Plan of Action was reviewed and updated in 2011.

The vision of the Ministry of Health Plan for Health Care of Persons with Disabilities 2011 – 2020 is to have equity in health care for persons with disabilities, and its mission is to ensure comprehensive health care for PWD at all levels of care (MOH, 2011).

The specific objectives of the Plan of Action are (i) To provide equal opportunities for health care for persons with disabilities, (ii) To empower individuals, families and communities for self-care and development of support services for persons with disabilities and (iii) To decrease the prevalence of disabilities through the provision of adequate medical rehabilitation services at all levels of care.

Under the Plan of Action, six major hospitals have been earmarked for the setting up of Child Development Centres. Besides that, MOH aims to expand early detection and intervention services to all health clinics by 2020, expand rehabilitation services to all health clinics with family medicine specialists (at least 10 clinics per year) and promote multidisciplinary team management.

#### 1.4.2.1 Health promotion and prevention programmes

Ministry of Health (MOH) programmes that work towards prevention of disabilities include antenatal/postnatal care, child health assessment, school health, immunisation, nutrition, injury prevention, and healthy lifestyle.

Early detection and prompt treatment can reduce morbidity leading to disabilities. More than 95% of children are accessible in the newborn period and in primary school under existing public health programmes, i.e. the Child Health Programme and School Health Programme.

Upon the birth of a child, parents are issued a Child Health Record for purposes of monitoring a child's growth, development and immunisation. In 2008, a revision of the Child Health Programme was instituted, with a view to improve screening and detection of medical and developmental problems in children. The Health Record for Baby and Child (0 – 6 years) includes a guided developmental assessment checklist at 3, 6, 9, 12, 18 months and 4 years, and the MCHAT (Modified Checklist for Autism in Toddlers).

It also contains health education for parents and carers to empower them to recognise developmental delay, and health care providers are strongly encouraged to take note of any such parental concerns. At scheduled health care appointments, developmental screening is done by health nurses using the checklists in the Health Record for Baby and Child, either at the health clinic or during home visits. Any child who is suspected of atypical development or possible disability is subsequently referred to a doctor at the health clinic.

In addition, MOH operates school health teams in every district. Under the School Health Programme, school children undergo a health screening examination in Years 1 and 6 in primary schools and Form 3 in secondary schools. The health screening examination includes physical examination, eye examination and hearing assessment. Any student suspected to have any sort of impairment is referred to the health clinic for further assessment.

Since 2010, the Ministry of Education have started a Literacy and Numeracy Screening (LINUS) Programme in all government and government assisted primary schools. The aim of this programme is to screen and detect students who have learning difficulties. These students will then be referred to health clinics for further assessment and confirmation of their special needs.

#### 1.4.2.2 Rehabilitation Services

The demand for rehabilitation services has increased rapidly and among the factors associated with this is the improvement in perinatal care (which has resulted in increased survival rates for children with disabilities).

The Programme for Care of Children with Special Needs at the Health Clinic encompasses the care and rehabilitation of children with special needs through detection and early intervention of developmental problems. The management of children with special needs at the health clinic is in line with the ministry's goal of providing comprehensive service close to the community.

The scope of services in the health clinic includes a complete developmental assessment of children with special needs, preparation of an intervention plan for new cases and periodic reassessment, early intervention activities, home visits and referral to various relevant specialties and agencies (MOH, 2006). The guideline on this programme states that planning and implementation of the care and rehabilitation plan for each child is best carried out by a Multidisciplinary Team (MDT) that comprises of personnel of various specialties from the hospital, primary healthcare and also other agencies in the community.

Rehabilitation services delivered by physiotherapists and occupational therapists have been in existence in MOH hospitals for decades prior to the year 2000, with services mainly focusing on physical rehabilitation for mobility and activities of daily living. In 1996, under the expanded scope of activities, rehabilitative services were introduced to selected health centres. With this expansion, rehabilitation services for persons with disabilities are currently provided not only in hospitals, but also in primary care facilities.

As of 2011, there are 242 (30%) health centres providing rehabilitative services for children with special needs (MOH, 2011). Services at these health centres are provided by paramedics such as public health nurses and medical assistants who undergo six-months training in acute hospital-based care and follow-up management for chronic conditions in primary care. Case management plans of the clients receive input from the physiotherapists (PT) and occupational therapists (OT) in hospitals, and clients are followed up at the health centres under the supervision of the hospital therapists. Since 2002, posts for PT and OT have been allocated to health clinics with heavy attendances. As of 2011, there are 55 occupational therapists, 56 physiotherapists and 8 medical social workers in the primary care setting.

Rehabilitation is also provided in community initiated Community Based Rehabilitation centres sponsored by the Department of Social Welfare. MOH provides technical input and outreach services to these centres.

### 1.5 Other Stakeholders

Many agencies are involved in the care of children with disabilities. The role of ministries and departments of health is to facilitate 'system integration' by providing resources, policy guidelines and other measures that encourage inter-agency and intersectorial collaboration (Greco & Sloper, 2004).

The different bodies involved in delivering services to children with disabilities are i) the Department of Social Welfare under the Ministry of Women, Family and Community Development, ii) the Ministry of Health, iii) the Ministry of Education, iv) private health care facilities and v) non-governmental organizations (figure 1.2).

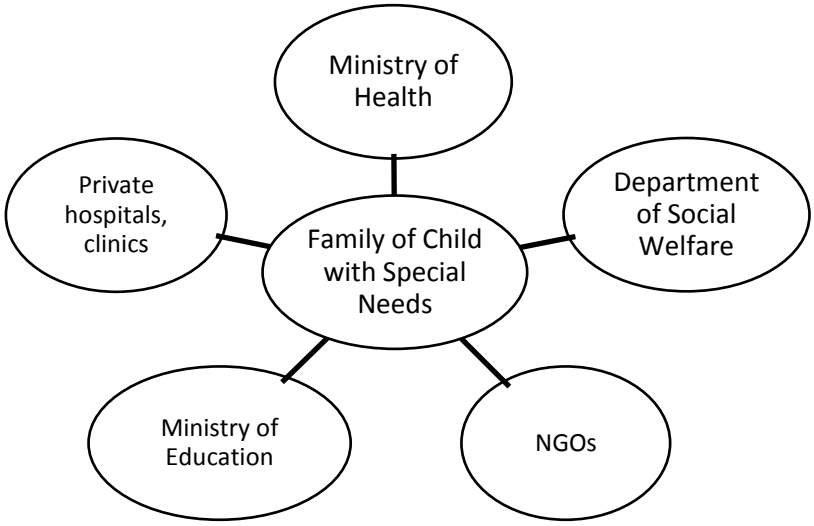


**Figure 1.2:** Different stakeholders involved in the care of children with disabilities/special needs in Malaysia

### 1.5.1 Department of Social Welfare

Some of the benefits that children with disabilities and their caregivers are entitled to are financial aid in purchasing medical equipment, exemption from import duty and sales tax for this equipment, financial aid of RM300 for PWD who are bedridden, study allowance of RM150 for primary and secondary school students, income tax relief, discounts on public transportation, free medical treatment at government health facilities (for medication, consultation and third class ward stays), and flexible working hours for civil servants to manage their child's needs and welfare.

Rehabilitation for children with disabilities is provided by community initiated Community Based Rehabilitation centres (locally known as PDK or *Pusat Pemulihan Dalam Komuniti*) sponsored by the DSW. In 2011, there were 468 PDKs providing service to 20,184 PWDs. The DSW supports the running of PDKs throughout the country by providing annual monetary grants for their operational expenses, programmes and activities. The PDKs provide rehabilitation services, special education and vocational training to children and young adults with disabilities. Activities at these

centres include teaching of basic daily life skills and basic reading, writing and arithmetic skills, recreational therapy and independent living training. CBR centres are preferred to institutional care and since they are within the community, the CBR concept helps in the acceptance and integration of children with disabilities in society.

The DSW also runs *Taman Sinar Harapan* homes which provide residence, care and rehabilitation for underprivileged children, including children with disabilities.

### 1.4.2 Ministry of Education

Primary education is compulsory in Malaysia since 2003. The Education Act 1996 and Education (Special Education) Regulations 2013 provide for special needs education for children with disabilities, stipulating that special education has to be provided in special schools or in designated primary and secondary schools.

Children who intend to enrol in special needs education are required to attend a probation period of no more than three months at a government or government-aided school to determine suitability. For children aged 4 – 6 years, early intervention programmes are provided by the MOE in Special Education Schools.

There are three options for children with disabilities under the national special needs education system: Special Education Schools, Special Education Integrated Programmes and Inclusive Education Programmes.

Special Education Schools are specific schools for children with disabilities. Of the 28 special education primary schools in Malaysia, 22 are for children who are hearing impaired, 5 for children who are visually impaired and one for children with learning disabilities. Of the 5 special education secondary schools, 3 are vocational schools, while 2 are academic schools for the hearing and visually impaired respectively.

Special Education Integrated Programmes (SEIP) are specific classes in mainstream schools dedicated to children with special needs. There are currently just below 2000 mainstream schools with SEIP, of which around 1300 are primary schools and around 670 are secondary schools.

In Inclusive Education Programmes, children with disabilities are integrated into mainstream classes. The principle of inclusive education is that children with or without special needs should learn together, and from each other, in the same classrooms (NECIC, 2012). Inclusive education is not limited to a specific disability. Any child with hearing, vision, speech, physical, learning or multiple disabilities, except for the severely disabled, can be placed in the same classroom as children without disabilities.

Since 2010, the Ministry of Education initiated the Literacy and Numeracy Screening Programme in all government and government assisted primary schools. The aim of this programme is to screen and detect students who have learning difficulties. Children with learning disabilities will be identified when they take the Literacy and Numeracy Screening (LINUS) tests conducted over the first three years of primary level education. When a child fails the LINUS tests repeatedly over the three year period, his/her parents will be asked to refer the child to the MOH for medical assessment and confirmation of their special learning needs. The other aim of this programme is to enable children who have special learning needs to be placed in a more suitable learning environment based on their learning capabilities. When a child is assessed to have learning disability, the decision to place the child in inclusive education programmes is up to the special education coordinator or the school principal in the school concerned.

There is a lack of a streamlined process of placement into the different special needs education options. The placement of the child is influenced not only by the nature of the child's disability but also the school's capacity to cope with the child. Schools may not

have trained teachers or the necessary teaching facilities to cater for the child. The quality of special education teachers varies and there is an extremely limited availability of speech and language therapists and educational psychologists in national schools. The Malaysia Education Blueprint 2013 – 2025 seeks to improve special needs education, but there have been criticisms directed at its approach and lack of detailed attention to the special needs education system (NECIC, 2012; UNICEF, 2014).

### 1.5.3 Non-governmental organizations

Non-governmental organizations (NGOs) that work with children with disabilities help to fill an important gap in the public system and at times, are seen to be one step ahead in advocating for CWDs. NGOs such as Asia Community Service in Penang, Association for Children with Special Needs Sibu, Malaysian Care, New Horizons, Wings Melaka and SPICES (Support for Parents, Infants and Children through Early Services) run non-profit learning and care centres that provide early intervention, learning, rehabilitation and training programmes for children with disabilities. Some also offer respite care services for caregivers. These NGOs play a crucial role in advocating for accessibility to health and education services for children with disabilities.

In Malaysia, the National Early Childhood Intervention Council was officially formed in 2011 to act as a forum to discuss, advocate, monitor and review all policies and actions related to early childhood intervention. The committee members are made up of paediatricians and representatives of NGOs. The council, in partnership with local organizers, hold a biennial National Conference on a rotating basis in various states throughout the country to increase local awareness and grass root participation.

### 1.6 Quality of life and participation for people with disability

Quality of life can be defined as the degree to which a person's physical, psychological, social, structural and material needs are satisfied. It is also often defined by life outcomes in terms of attaining meaningful goals, activities and relationships (King et al., 2002). Quality of life results when people's needs are met and therefore provides legitimacy to the concept of "need" in driving service delivery (King et al., 2002). A mismatch between a child's functional abilities and the available environmental supports that promote participation of both the child and other family members in daily life activities gives rise to a need for ancillary and enabling services (Benedict & Farel, 2003).

Services structured to address children's needs and the needs of those around them will contribute to their community participation and quality of life. This quality of life approach works to ensure that people with disabilities and their families experience a high level of well-being, despite their limitations. Thus, the focus is to maintain adequate levels of functioning in areas that are important to the individual or the family (Gibson et al., 2009; Samuel, Rillotta & Brown, 2012).

Participation in activities is both the desired outcome and process by which people attain competence, establish meaningful relationships and attain life satisfaction. People with disabilities face many obstacles and restrictions in participation brought about by economic realities and environmental factors, including physical (lack of suitable infrastructure), social (people's attitudes) and political (lack of legislation supporting inclusion) barriers.

Barriers in access to care affect the participation and social inclusion of children with disabilities. Parents reported that their children encountered the highest perceived barriers in the physical or structural environment, followed by barriers in getting

services and assistances, barriers related to work and school, policy barriers and lastly barriers related to attitudes and supports (Kertoy et al., 2012).

The social approach to disability is advocated as a model to be used clinically to meet the intervention needs of children with disabilities and their families. If all the health care and support needs of this vulnerable group are met by disability related services, children with functional impairments would be able to participate in society and consequently need not be considered "disabled".

### 1.7 Rationale of study

This study on health care services for children with disabilities was undertaken with the view that children with disabilities, like any other children, deserve lives of quality and services should be available to help make this a reality. The demands for provision of services for children with disabilities have increased with the increase in awareness about people with disability and the move from charity based services to rights based services. There is limited child disability research and data in Malaysia, especially looking at outcomes of the service delivery system and service equity. Furthermore, as Malaysia is undertaking a health sector reform in the near future, service provision for persons with disabilities should be explored, to align resources in order to achieve the mission of the MOH Plan for Health Care of PWDs.

One of the main aims of the Biwako Millenium Framework is that by 2012, all infants and young children aged 0 – 4 will have access to and receive community based early intervention services (ESCAP, 2003). Unmet rehabilitation needs can delay discharge, limit activities, restrict participation, cause deterioration in health, increase dependency on others for assistance, and decrease quality of life (WHO, 2011).

Although there have been efforts at the national level to enhance the status of persons with disabilities in Malaysia, a look at the provision of services for children with disabilities would be useful to see how well the country is performing in achieving disability-inclusive development goals. Children with disabilities are an even more vulnerable group among people with disability because children have the least direct control over what happens to them and have the least direct access to available resources.

One of the outcomes that we hope to get from the Programme for Care of Children with Special Needs is that ALL children with special needs receive ALL the rehabilitation services that they need. It has been alleged that less than 20% of Malaysian parents use disability services regularly and only 10% of parents are actively engaged in their child's rehabilitative process (Amar-Singh, 2008).

There are few published works on children with disabilities in developing countries and in Asia. A review to examine what is the current available research on childhood disability in low and middle income countries found that there were many gaps, especially in the areas of intervention, service utilization, and legislation (Maulik & Darmstadt, 2007).

A number of countries such as the United States, Australia and New Zealand conduct national disability surveys (AIHW, 2006; SNZ, 2006; Bramlett et al., 2014), but Malaysia has so far not done so. Information about disability services in Malaysia is mostly derived from compilation of statistics from relevant departments such as the Ministry of Health and Department of Social Welfare.

Small scale studies have been conducted, either in a specific setting or with a specific group of children with a certain type of disability, but these seem to have minimal implications on the overall provision of services. The few Malaysian studies involving

children with disabilities have largely focused on specific clinical outcomes (Satwant, Subramaniam, Prepageran, Raman & Jalaludin, 2002; Liza-Sharmini, Azlan & Zilfalil, 2006; Mohd-Ali et al., 2006) and parental stress (Ong, Afifah, Sofiah & Lye, 1998; Ong, Chandran & Peng, 1999; Norizan & Khadijah, 2010). Preliminary studies on quality of life (QOL) of families of children with disabilities in Malaysia have been published (Rahman et al., 2011; Clark, Brown & Karrapaya, 2012) but were limited by their small sample sizes and lack of generalizability.

To the best of this author's knowledge, so far no study has been done to look at unmet health care service needs among children with disabilities in Malaysia. As for studies on family needs of CWDs, to date, there has only been one published local study using the Family Needs Survey (Suriati, Zainiyah, Lye & Norlijah, 2011). However, Suriati et al only studied children attending community rehabilitation centres (CBR), which excluded a majority of children with disabilities who were in the mainstream or special needs education system, or those staying at home. The responses from families using available supports such as the CBR and actively involved in their child's rehabilitation are expected to be very different from those who are not.

There is a need for better data collection about services for children with disabilities and their families to inform service planning. Documents containing expert opinion are available (Amar-Singh, 2008, 2013) but no concrete study has been done to look at whether disability services in Malaysia are meeting the needs of children with disabilities and their families.

The organization and provision of disability services or for that matter, health or social services in general, differs from country to country even though countries may follow a particular model. Different societies have different cultural outlooks towards having a child with disability due to differences in social and religious norms and expectations.

There are also cross-cultural differences in willingness to openly report on perceptions, which makes for interesting study, especially in a multi-ethnic society like Malaysia.

Magnitude of unmet needs and the type of services with unmet need may differ between countries and regions depending on what are the perceived needs of the population studied. Access problems also differ depending on the availability and quality of existing services.

This study hopes to find out the prevalence of unmet need for health care services for children with disabilities in Penang, a state in Northern Malaysia. In addition, the study aims to find out the service needs of families or caregivers of children with disabilities. Information on service utilization, financial burden and social support will also be gathered in view that recognition of the financial impact and social support systems available to families of children with disabilities can help guide the planning and provision of family support services.

Decisions on allocation of human resource and budget take into account that disability services do not just affect one particular group of disability but needs to be overarching across all types of disability. For example, the decision to create more posts for speech therapists in government services will not just be influenced by the number of people with speech disability, but also on the number of people with other disabilities who have speech problems.

Under the 1Care health system reform, social health insurance is being proposed as a means of financing health care, with the government subsidizing vulnerable groups, including children, elderly and the disabled. Data on disability that is important for the planning, implementation, monitoring, and evaluation of inclusive policies are currently lacking in the country.

Thus, it is timely for a study focusing on the vulnerable population of children with disabilities to be conducted in Malaysia. Although this study does not encompass the whole nation, it gives some preliminary information on the situation of services for children with disabilities, and could serve as a foundation for a bigger, nationwide study. Since there is so little research on child disability services in Malaysia, this study will inform important baseline data from which to plan both services and future research.

Unmet needs are used to assess equity of access to health care across population subgroups and can serve as indicators of national or local government performance. In line with the vision of Malaysia's Health Care Plan for Persons with Disabilities which calls for equity for PWDs, it is imperative that health service providers understand what are the needs and unmet needs of children with disabilities and their families. Findings from this study can help inform service providers on which areas to prioritise in the provision and development of health care services for children with disabilities and support services for their families in Malaysia. Unmet needs can be alleviated if service providers know which services to allocate more resources, and what are the barriers to access that need to be removed.

## 1.8 Outline of the thesis

This thesis is divided into six chapters. Chapter One has provided a background on disability locally, as well as the motivation for embarking on a study on health care services for children with disabilities in Malaysia. Chapter Two discusses the available literature on health care services for children with disabilities and their caregivers. It also addresses information from the literature which was used to help develop the study methodology. Chapter Three then presents the methodology of the study, while the results of the study are presented in Chapter Four. Chapter Five contains a discussion on the findings of the study according to the research objectives. It also includes the strengths and limitations of the study. Lastly, a summary of the study findings, its public health implications and recommendations for future research are presented in Chapter Six.

## 1.9 Conclusion of chapter one

An understanding of disability, in terms of the definition, prevalence, policy, programmes and stakeholders involved, is important and relevant for the intended research. Approximately one third of new registrations of persons with disabilities every year in Malaysia are children. One of the main stakeholders involved in the care of children with disabilities is the Ministry of Health. The MOH aims for equity in health care for children with disabilities through the provision of comprehensive health care services. This study will examine whether health care services are provided in an equitable manner for CWDs.

# CHAPTER 2: LITERATURE REVIEW

## 2.1 Introduction

The main themes from the available literature are health care service needs of children with disabilities, family needs, barriers to care and care burden. The Behavioural Model of Health Services Use is introduced as the guiding framework of this study. To answer the question on how to conduct the study, an examination of how disability data is collected, how health care services are assessed and the study instruments used in other studies on similar topics was performed.

## 2.2 Definition of terms in the literature review

Researchers and policy makers use classification systems to identify and target populations for policy initiatives. From a health services research point of view, to study the group of people who would benefit from services, first we need to identify who they are.

Operational definitions for children in need of services can vary with researchers using different terms including “children with disabilities”, “children with functional limitations”, “children with chronic conditions” and “children with special health care needs”. At the core of it is the aim to identify who are the children whose social participation is compromised, and thus may be in need of ancillary or enabling services. The decision on which operationalization to use depends on the objectives of the study and also the study setting, for example which term is commonly used and understood in a particular society.

In the US and in Europe, the operational definition of "children with special health care needs" is commonly used for health services research. In the past, health care needs in children were defined by concepts of condition or diagnosis lists, functional limitation or disability. More recently, the definition of children with special health care needs was derived from health care utilization, whereby the use of certain health care services and the frequency of using those services indicated that the child had special needs. For example, the US Maternal and Child Health Bureau defines children with special health care needs as "children who have or are at increased risk for a chronic physical, developmental, behavioural or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson M. et al., 1998).

Both the advantages and disadvantages of using the operationalization of children with special health care needs are related to its definition. Besides identifying children based on their functioning consequences, the definition also emphasizes their service need consequences. A definition that relies on people's reported use of services to identify them would miss out on those who did not use services, especially in resource poor countries where health systems are weak and disability services are minimal or even absent. The use of the definition "children with special health care needs" is therefore preferred in settings where services are well established and with fewer access problems.

"Children with special health care needs" covers a broader range of children than "children with disabilities" because the term includes children with chronic conditions such as epilepsy, asthma, arthritis, atopic eczema, diabetes and other health conditions conventionally not considered disabled.

At this point in time, the conceptual definition of "children with special health care needs" is not yet broadly applied in Malaysia. The term "children with disabilities" is more established and well known in Malaysian society, and Malaysia has a Disability Act which delineates the meaning of disability clearly. Even though the term "children with special needs" is also commonly used, it is often regarded as a more politically correct way of addressing children with disabilities.

Several parties actually do not like the term "disabled" because it is perceived to have a negative connotation, but for clear understanding and practical use in Malaysia, there is an advantage in using this term. Malaysia has a system to detect children with disability but not to detect children who have special health care needs, unlike in Western countries, where nationwide surveys are conducted to screen their child population for those who are in need of ancillary and enabling services.

The literature reviewed here does not distinguish between children with special health care needs (CSHCN), children with chronic conditions, children with functional limitations and children with disabilities as there is considerable overlap in the needs of these children and their families.

Children with disabilities are in fact the most vulnerable group among all children with special health care needs. CSHCN with disabilities had more severe and less stable health conditions than other CSHCN, even after adjusting for socio-demographic characteristics, indicating their increased need for services (Houtrow A.J., Okumura M.J., Hilton J.F. & Rehm, 2011). They have even been shown to have higher rates of health care utilization and more difficulty accessing services than other CSHSCN (Houtrow, Okumura & Rehm, 2010).

## 2.3 Health needs assessment

Health needs are needs that can benefit from health care but also those that incorporate wider social and environmental determinants of health (Wright, Williams & Wilkinson, 1998). Health needs are differentiated into needs, demands, and supply. *Need* in health care is defined as the capacity to benefit. *Demand* is what patients ask for; which can depend on the characteristics of the patient or on the media's interest in a particular service. *Supply* is the health care provided. This will depend on the interests of health professionals, the priorities of policy makers, and the amount of money available.

Health needs has a broad definition but for the purposes of health services research, health care needs relates to needs where the individual requires specific existing health care services and may benefit from fulfilment of these needs (Schmidt, Thyen, Chaplin, Mueller-Godeffroy & Bullinger, 2008). The term health care needs overlaps with related concepts of health needs, health demands and health service supply. Although health demands and health services supply may give an indication of health care needs, demands can be triggered by secular trends, and supply is very much driven by market forces.

Health needs assessment is a systematic approach to understanding the needs of a local population (Wright et al., 1998). It involves describing health problems of a population, identifying inequalities in health and access to services, and determining priorities for the most effective use of resources. Needs assessment is important so that health authorities can tailor services to their own populations. Different issues or populations require different approaches to studying health needs.

Health needs in this study are considered in terms of services that can be supplied to the child or the family. A mismatch in the demand and supply of services raises questions about the allocation of scarce resources. The term "equity audit" is used to determine if healthcare resources are being used in accordance with need.

It is important to evaluate the extent to which limited services are provided to the families who most need it. Chadwick, Beecham, Piroth, Bernard and Taylor (2002) found that caregivers of children with more severe intellectual disability and behaviour problems needed more respite care but were not more likely to get it. On the other hand, respite care was more often provided to families of children with disabilities with more children despite they were not more likely to indicate a need for it.

The definition of health care needs in childhood started to evolve after 1990. Prior to that, services for children with disabilities primarily targeted their medical and therapeutic needs in relation to their diagnosis (King, King, Rosenbaum & Goffin, 1999). In the 1990s, the focus shifted to programmes which help develop specific skills to improve the child's function. At the time, these programmes were not community based as they were not offered in home and school environments. After the 1990s, a more holistic view of children's needs was adopted. This influenced the trends in health and social services, with more emphasis being given to the interactions between the child and his/her environment, quality of life, and focusing on the strengths of the child rather than weaknesses.

Children and youth with disabilities have complex needs which change as the child develops and service programmes should be available throughout this life transition. For example, adolescent needs tend to focus on vocational and adaptive issues related to having a long term condition, while need for help with child care is more prevalent in younger children (Perrin, Lewkowicz & Young, 2000).

Children's dependence on adults means that research on care must take into account the child's family. In the past, interventions for children with disabilities used to focus on the provider as the 'expert', but since the 1980s, the focus has shifted to 'families' as the experts. With the recognition of the rights of people with disabilities and the paradigm shift from "fixing the individual" to "fixing the environment", the family has been ushered to the forefront of caregiving. Families form the primary structure to the functioning and ongoing stability of societies (Samuel et al., 2012). Families also act as the main caregivers and decision makers regarding disability support (Clark et al., 2012).

Having a family member with a disability is often challenging for each member in the family, and families are not always able to function well as a result. Perceived impact of services on the child is related to perceived impact on the family (Bailey, Nelson, Hebbeler & Spiker, 2007). Parents generally focus their attention on immediate and direct concerns, i.e. how to best address their child's present needs and how to access services for their child (Westling, 1997). The term 'family need' describes family members' desires for information, services and supports to achieve goals related to their family (Almasri et al., 2011). A family's need for services can be defined as a family's desire for services to be obtained or outcomes to be achieved (Bailey Jr & Blasco, 1990).

Family assessment and family focused interventions are now an integral part of managing a child with disability. Family assessment can help interventionists (i) understand the needs of the child, (ii) understand the needs of the family, (iii) understand the family context of such needs, (iv) determine interventions required to meet child and family needs, and (v) motivate the family to engage in the intervention (Bailey Jr & Simeonsson, 1988).

Needs based interventions are recommended as best practice in paediatric rehabilitation (Almasri et al., 2011). The Life Needs Model of Paediatric Service Delivery (King et al., 2002) groups services according to their focus on five types of needs: (i) need for foundational skills (minimizes impairment), (ii) need for applied skills (improves functioning), (iii) individual's need for support and information, (iv) family's needs for support, information and skills, and (v) community members' needs for information and education. According to the ecological model of child-in-family-in-community model, the needs and goals of the child, their families and the communities where they live are equally important components of service delivery (Washington & Schwartz, 1996; King et al., 2002; Kertoy et al., 2012).

A narrow focus on services for children with specific disability conditions is not desirable, as these children share many similar health issues. Services are not distinguished by disability condition although different therapy and technology modalities apply to individual children. Furthermore, similarities of issues affecting families of children with disabilities cut across diagnoses, such as problems with financing care, physical burdens of care, lack of coordination of services and limited access to needed services.

### 2.4 Child's health care service needs and unmet needs

Ancillary and enabling services are provided to maximize a child's ability to participate in family, school and community life and to enable families of children with special needs to adapt to their child's condition. Benedict and Farel (2003) defined ancillary services as allied health and related professional services typically provided in education, rehabilitation, home health or community based clinic settings such as audiology, occupational therapy, physical therapy, speech therapy and social work.

Enabling services are programme services and products such as special equipment, paid personal care assistance, respite care, transportation or environmental modifications intended to assist families in caring for a child with chronic conditions.

Studies in developed countries have found the prevalence of unmet need for services among children with disabilities to be less than 30% (Clark & MacArthur, 2008; Baillargeon, Bernier & Normand, 2011; Litt & McCormick, 2015)

The Family Partners Survey (FPS) 1998 – 1999 measured unmet need for six different types of services - specialty doctor, speech therapy, occupational therapy, physical therapy, home health and mental health services (Warfield & Gulley, 2006). Prevalence of unmet needs was highest (12%) for mental health services, between 8 to 11% for speech therapy, occupational therapy, physical therapy and home health services, and only 3.4% for specialty doctors.

The first US National Survey of Children with Special Health Care Needs (NSCSHCN) in 2000 – 2002 showed that there was an unmet need for specific health care, defined as any of 14 primary and specialty care services, ancillary services, supplies and equipment in 18% of children with special health care needs (van Dyck, Kogan, McPherson, Weissman & Newacheck, 2004). Out of 74.4% of CSHCN in the national survey who needed routine physician care, 3.2% were unable to obtain these services, and out of 51.0% who needed subspecialty physician care, 7.3% reported not receiving all needed specialty care (Mayer, Skinner & Slifkin, 2004). Prevalence of unmet needs for communication aids was higher than for vision aids or mobility aids (Dusing, Skinner & Mayer, 2004).

The results of the 2009 – 2010 US National Survey of Children with Special Health Care Needs showed that 20.2% of CSHCN had an unmet need in one or more areas of primary and specialty care services, ancillary services, and assistive devices (Litt &

McCormick, 2015). Unmet needs for each service type in the NSCSHCN and FPS were generally quite low.

When comparing children with disabilities and other children with special health care needs, more than twice as many children with disabilities (11.3%) reported unmet need compared with other CSHCN (5.0%), even after controlling for socio-demographic characteristics (Houtrow A.J. et al., 2011).

Few studies have been done on disability related services in low and middle income countries (LIMC) (Maulik & Darmstadt, 2007). Approximately 50 – 75% of children with disabilities in resource-constrained settings are estimated to have unmet needs for rehabilitation services and 60 - 80% had unmet need for assistive devices (2011). A study in South Africa revealed that 74% of children with disabilities who were judged to need physiotherapy, occupational therapy and/or speech therapy by researchers, and 72% who needed assistive devices, did not receive them (Saloojee, Phohole, Saloojee & IJsselmuiden, 2007). Unmet needs are more considerable in rural areas where poverty is a barrier in accessing services (Pongprapai, Tayakkanonta, Chongsuvivatwong & Underwood, 1996; McIntyre, Newland, Ison, Salmon & Pearce, 2009; Magnussen, 2011) .

In regards to preventive medical care, unmet medical needs in this area were minimal among children with disabilities using ambulatory services at a children's hospital in Germany (Thyen et al., 2003). Unmet need for having a regular doctor was 2.2%, monitoring of child's growth and development 1.2%, getting immunizations 1.1% and attending well-child visits 0.8%.

In contrast, only slightly over one third of children with disabilities in Taiwan received preventive health care (Tsai, Kung & Wang, 2012). For children with disabilities, preventive health services such as physical examinations and health education are not

readily distinguished from therapeutic medical care services if they come from the same providers such as doctors, dentists and nurses. The study was conducted based on data on utilization of preventive health services and health insurance medical claims from a nationally administrative database, thus it was limited by the information available from the database. Preventive health services already incorporated into therapeutic medical care services were not captured in the database.

Unmet need for different types of services varies, with mental health services usually being the most unmet, and specialist physician services and special medical equipment the least unmet (Warfield & Gulley, 2006; Schmidt, Thyen, Chaplin & Mueller-Godeffroy, 2007).

Children with disabilities usually need specialty or sub-specialty care. Receipt of such care ensures that complications particular to a certain health condition or disability can be recognized early. These specialty or sub-specialty physicians would also have better knowledge and access to newer treatment modalities.

Help locating a physician who understands the child's needs were reported by ≤15% of parents as definite needs (Bailey Jr & Simeonsson, 1988; Farmer, Marien, Clark, Sherman & Selva, 2004). On the other hand, a Malaysian study by Suriati et al. (2011) found that quite a high proportion (59.7%) of respondents needed help locating a doctor who understands their child's need. The proportion was also high in a Japanese study, whereby 57.6% of mothers and 50.6% of fathers reported needing this help (Ueda et al., 2013).

The difference in findings could be due to the population studied. Both Suriati et al and Ueda et al included children with learning disability and pervasive developmental disorders, whose problems are not strictly medical and therefore may not be within the scope of many doctors.

The five services perceived to be most needed by children and youth with special needs in a pilot study of an outcome measurement system conducted in Ontario, Canada were speech and language therapy (72%), physical and occupational therapy (72%), medical evaluations, nutrition and nursing care (47%), special education (44%) and use of adaptive equipment (39%) (Kertoy et al., 2012).

Speech therapy is a service frequently used by children with developmental disabilities (Betz et al., 2004). Results from the second US National Survey of CSHCN 2005 – 2006 estimated the prevalence of speech difficulty to be around 4 times higher than the prevalence of hearing difficulty, both in the general population and in the population of CSHCN (Kenney & Kogan, 2011). A qualitative study showed that carers of children and youth with developmental disabilities and challenging behaviour reported a lack of speech and language therapy (Wodehouse & McGill, 2009). Parents of children with intellectual disability expressed the need for consistent, intensive speech therapy and the need for ongoing therapy into adulthood (Carroll, 2010). Interestingly, unmet need for communication aids was higher than unmet need for hearing aids among CSHCN with speech and hearing difficulties (Kenney & Kogan, 2011).

Children with disabilities are at higher risk of vision problems such as refractive errors and poor eye accommodation than children without disabilities (Woodhouse, 1998). Thus, children with all forms of disability, not just those with visual disability, have the right to optometry services.

Research has highlighted that health care providers should be more vigilant about detecting emotional or behavioural health conditions and referring children with these conditions to mental health services (McCarthy & Boyd, 2002; Warfield & Gulley, 2006; Pastor & Reuben, 2009). Children with a behavioural condition had a significantly higher mean number of needed services than those without (Warfield &

Gulley, 2006). Children with learning disabilities are particularly vulnerable. Students in special education were more likely to have serious emotional or behavioural problems compared to students not in special education (Pastor & Reuben, 2009). A majority of people with intellectual disability with persistent challenging behaviour from childhood and even those with an established childhood psychiatric disorder did not receive specialist mental health care (McCarthy & Boyd, 2002).

More than half of youths with intellectual disability and behavioural/emotional problems in a Dutch study needed mental health care (56.7%), but more than half (59.4%) of them also did not have this need met (Douma, Dekker & Koot, 2006). The Canadian Participation and Activity Limitation Survey (PALS) 2001 found that 29.8% of children with impairment of psychological functions were being refused a child care programme or service and 24.6% were not receiving health services when needed (Baillargeon et al., 2011).

In a study among families of children with chronic health conditions attending primary care clinics in the US, most families had access to and were satisfied with their child's health care services except for mental health care (Farmer et al., 2004). Primary care physicians caring for CSHCN reported satisfaction with the availability of specialist care, emergency room and hospital care, but dissatisfaction with mental health services (Davidson, 2002).

Dental care is a frequently cited unmet need for CSHCN (Desai, Messer & Calache, 2001; Lewis, 2002). Children with disabilities have poorer oral health and greater needs for both preventive and treatment oral health services than non-disabled children (Hennequin, Moysan, Jourdan, Dorin & Nicolas, 2008). Oral health problems which may be encountered are plaque, caries, periodontal disease, halitosis, drooling and food packing between the teeth (De Jongh, Van Houtem, Van Der Schoof, Resida & Broers,

2008; Aburahma, 2011; Norwood Jr & Slayton, 2013), especially in children with poor orofacial motor control such as cerebral palsy.

Children with severe intellectual disability and behaviour problems are particularly challenging to treat, being non-cooperative due to fear and lack of understanding of daily oral care or dental procedures (De Jongh et al., 2008). Lower functioning level was associated with more tooth decay and periodontal disease (Desai et al., 2001). However, despite many children with disabilities only requiring simple dental treatment, their preventive and treatment needs remain unmet (Desai et al., 2001). Non-institutionalized children with severe mental disabilities in the Netherlands had poor oral health and received a relatively low degree of quality dental care (De Jongh et al., 2008).

Bailey Jr and Simeonsson (1988) found that 12% of mothers and 6% of fathers reported needing help locating a dentist who will see their child, while Farmer et al. (2004) and Ueda et al. (2013) reported a proportion of around 37%. In Malaysia, Suriati et al. (2011) reported 60.4% of caregivers needing help locating a dentist for their child.

Poor nutritional status and growth failure are common in children with neurological impairments, especially those with a greater degree of motor impairment (Sullivan et al., 2002). These children should receive nutritional assessment and intervention as part of their overall care. Examples of nutrition intervention services are techniques for food preparation, stimulation of the eating process and monitoring of specialized feedings (Taylor, Wheeler, Taylor & Griffin, 1996).

Other children with disabilities without neurological impairment may also suffer from poor nutritional status and feeding difficulties. Parents of children with intellectual disability and developmental or behavioural problems in particular may face problems getting the child to eat or on the opposite end, to reduce their food intake.

In a survey on children with motor problems attending a referral clinic for developmental conditions, the most common diagnosis for children who were prescribed medical equipment was cerebral palsy (Peredo, Davis, Norvell & Kelly, 2010). This was followed by intellectual disability, genetic abnormality, spina bifida and neuromuscular diseases.

In order for assistive technology to facilitate the social inclusion of the child with disability, the equipment prescribed should be task specific and relate to social roles, besides being suitable to the environment and for the family (Ried et al., 1995). Types of equipment include orthotics, bath chairs, seating devices, standers, augmentative communication devices, walkers and gait trainers.

In the 2002 New Zealand Household Disability Survey, 24% of parents of children with physical disability reported an unmet need for special equipment, 11% for home modification, 10% for help around the house, and 4% for modification to a private motor vehicle (Clark & MacArthur, 2008).

Unmet needs were lowest for supply of medical equipment or physical aids (<4%) for most child conditions in the European Child Health Care Questionnaire on Satisfaction, Utilization and Needs (CHC-SUN) pilot study, compared to other child specific services (Schmidt et al., 2007). In another European study, only 1.1% of families did not have anyone counsel them about special appliances (Thyen et al., 2003).

Home health service was one of the services with high access problems (Warfield & Gulley, 2006), with 29.7% of those reporting a need for home health services having problems finding providers with skill/experience, while 25.1% had difficulty in getting an adequate number of visits. Children who are expected to need home health services are those with chronic special health care needs requiring assistive technology.

## 2.5 Family needs

The needs of families living with a child with a chronic condition or disability are fairly universal. Family needs are comprised of generally the same dimensions, except that some aspects may hold more importance than others for some groups (Samuel et al., 2012). Generally, people of different socioeconomic or ethnic backgrounds do not differ in the nature of caregiving they would like to receive, i.e. parental perceived need of whether a service would be beneficial to the child (Schmidt et al., 2008). Family needs in the dimensions of support, information, finances, child care and professional services for the child have been identified to be independent of the child's diagnosis (Perrin et al., 2000).

Family or caregiver needs are a reflection of what services caregivers perceive to be important but are lacking to improve their quality of life. The role of disability service systems to support families should be to help families to function better. Access to information and services, financial barriers, school and community inclusion, and family support are prominent themes which have emerged from family needs research (Resch et al., 2010).

Using the Family Needs Survey, Farmer et al found that 93% of mothers of children with chronic health conditions reported one or more unmet needs; 87% reported needing help with at least one item on information, 80% with social support, 60% with finding community services, 51% with family functioning, 50% with finances and 40% with explaining their child's condition to others (Farmer et al., 2004).

Only 5.1% of families of children with special health care needs in the first US NSCSHCN 2000 – 2002 had an unmet need for family support services, but in this survey, only information about respite care, genetic counselling and mental health care or counselling support services was requested (van Dyck et al., 2004).

### 2.5.1 Information needs

Most research indicates that families of children with special health care needs reported needing information most. A literature review of the needs of families of children with physical disability revealed 'information needs' taking an important place (Siebes, Ketelaar, Gorter, Alsem & Jongmans, 2012). In addition, primary care physicians caring for CSHCN reported dissatisfaction with access to community resources and information available to families (Davidson, 2002).

Perrin et al. (2000) found that >50% of both mothers and fathers endorsed the need for help for "Information needs". The most frequently endorsed need among parents of children with chronic health conditions was for "information about services the child might receive in the future" (74%), "reading material about other parents with a similar child" (57%) and "information about services presently available for the child" (54%) (Farmer et al., 2004). More than 50% of both fathers and mothers of handicapped infants definitely wanted information about how to teach their child, information about current and future available services, and reading material about parents who have a child similar to theirs (Bailey Jr & Simeonsson, 1988).

Suriati et al. (2011) found that for all the items in the Information Needs construct of the Family Needs Survey (FNS), more than 75% of Malaysian families needed help with each item. The percentages of mothers and fathers expressing a definite need for help in the Japanese version of the FNS were also highest for the construct of Information Needs (Ueda et al., 2013).

In a Dutch study on parents of children with motor or multiple disabilities attending therapeutic toddler classes, at least 50% of both mothers and fathers expressed needs for information concerning the child (Hendriks et al., 2000). "Need for information on community services" was most frequently reported. In another study in the Netherlands,

68% of parents of youths with intellectual disability and behavioural/emotional problems reported needing more information, and 48.7% of them had this need unmet (Douma et al., 2006).

The service perceived to be most needed by families of children and youth with special needs in Canada was information about where to get services for their child, with 50% of respondents endorsing this need (Kertoy et al., 2012). In addition, 35% of families also endorsed the need for information about where to get services for the family.

In contrast, Thyen et al. (2003) found that relatively few parents reported unmet needs for information compared to other studies. Unmet need for information on parent groups and self-help organizations was 17.8%, information on social services was 13.9% and information about family support programmes was 19.2%. Unmet need for general advice about educational or behavioural problems was 22.5%, while 6.2% of families did not have their child's condition, disability or developmental delay sufficiently explained to them, and 9.9% did not have someone discuss with them whether their child's condition or disability runs in the family.

The difference in findings could be due to the different emphasis in the questions (wanting more information vs assessing whether provision was sufficient). Thyen et al asked whether needed services were received, while other studies asked respondents to rate their need for help. Despite unmet need for information being relatively lower compared to other studies, nevertheless within the study itself, unmet need for information was still higher than unmet need for receiving preventive medical care.

Unmet needs were high for information about services for the child and also information on ways to improve the child's health and development. Parents of adolescents with intellectual disability and behavioural/emotional problems needed parental counselling to better handle their child's problems (48.8%), and this need was

highly unmet (64.5%) (Douma et al., 2006). In the European CHC-SUN pilot study, the prevalence of unmet needs was highest for telephone counselling by a medical professional (22.7%) and for health education (21.4%) (Schmidt et al., 2007). Locally, 75% of Malaysian parents indicated they wanted more time with their child's teacher or therapist (Suriati et al., 2011).

### 2.5.2 Psychosocial support needs

Having more time for oneself and talking to someone in the family and friends about problems were needs frequently expressed by mothers (Bailey Jr & Simeonsson, 1988; Suriati et al., 2011; Ueda et al., 2013). Besides that, parents generally wanted opportunities to talk to other parents of children with similar problems (Bailey Jr & Simeonsson, 1988; Hendriks et al., 2000; Suriati et al., 2011; Ueda et al., 2013). More than 50% of mothers endorsed contact needs, which included having discussion groups and contacts with other similar families (Perrin et al., 2000).

Bailey and Simeonsson, Farmer et al reported less than 25% of parents expressing the need for professional psychosocial supports. In Malaysia, Suriati et al reported 56% of caregivers wanted to meet more regularly with a counsellor. The reported percentage for need to meet and talk with counsellors is higher than the earlier mentioned studies, but this need was rated lower than need to talk with family members (63.2%) and friends (69.1%). In Japan, around 45% of mothers and fathers wanted to meet with a counsellor, while around 17% of fathers and 25% of mothers wanted to talk to family members or friends (Ueda et al., 2013).

Psychosocial support services are well established in certain countries. The least unmet need was having a friendly ear/ someone to talk to (24.7%) in a study on parents of youths with intellectual disabilities and behavioural/emotional problems, despite being

the most needed at 78.1% (Douma et al., 2006). Among parents of children with disabilities from a hospital in Germany, unmet need for having someone who understands the special problems of raising a child with disability to talk to was 15.7% (Thyen et al., 2003). In the CHC-SUN pilot study, unmet need for self-help groups was 20.5% and for psychological counselling was 19.4% (Schmidt et al., 2007).

### 2.5.3 Financial needs

Japanese families needed more help paying for special equipment, for therapy and for child care compared to paying for daily expenses (Ueda et al., 2013), but this was the opposite for Malaysian families. Malaysian families expressed needing assistance paying for daily expenses the most and assistance paying for babysitting or respite care the least compared to other expenses (Suriati et al., 2011). Families of very young children also reported needing more support with daily expenses compared to paying for special equipment, therapy and child care (Bailey Jr & Simeonsson, 1988). In a Canadian study, 38% of families of children and youth with special needs reported needing money to help pay bills (38%) (Kertoy et al., 2012).

Job counselling was rated by only approximately 10% of mothers and fathers as definite needs (Bailey Jr & Simeonsson, 1988; Farmer et al., 2004). In the Malaysian study, only 16.3% of respondents reported needing help getting a job (Suriati et al., 2011). However, this need was quite high in Japan, where the reported need was 58% in mothers and 56% in fathers (Ueda et al., 2013).

### 2.5.4 Child care and respite care needs

Child care need was reported by 42% of Canadian families (Kertoy et al., 2012). Help finding a babysitter or respite care providers were reported by 52 – 66% of Japanese families (Ueda et al., 2013), while it ranged from 27 – 40% in other studies (Bailey Jr & Simeonsson, 1988; Farmer et al., 2004; Suriati et al., 2011).

Parents of children with disabilities have a heavy care burden. They need to take a break in order to rest and recharge their energy to manage and cope with their daily lives. They also need time for other children and for each other, as well as to do something else other than being a parent. Parental perception of unmet respite needs was correlated with higher caregiver stress and lower resilience (Larkin, Marx, Gordon & Johnston, 2012).

Respite care can be defined as child care services that enable caregivers to have more time for themselves, and to attend to other family responsibilities. Respite can be provided as direct assistance with caring duties or supervised child development programme which have a respite effect (Larkin et al., 2012).

Caregivers of people with disabilities in Australia are heavy users of respite services. The number of respite service users increased by 50% over a 5-year period from 2005 – 2010 (AIHW, 2014). The Canadian PALS showed that almost 40% of caregivers needed at least one aspect of respite care (Baillargeon et al., 2011). Caregivers needed help or additional help with everyday housework (19.7%), to attend to other family responsibilities (30.8%) and to take time off for personal activities (39.4%).

It has been suggested that there is a shortage of family support especially focusing on respite care (Brodin & Lindstrand, 2005). In a qualitative study on carers of children and youth with developmental disabilities and challenging behaviour, carers reported a lack of respite services (Wodehouse & McGill, 2009). Highest unmet respite needs in

children with cerebral palsy were need for more respite time followed by appropriate respite care providers (Larkin et al., 2012).

Percentage of parents who received insufficient or no help in the subscale of "need for respite care" was over 50% for both mothers and fathers in a Dutch study of parents of toddlers with motor or multiple disabilities (Hendriks et al., 2000). Respite care was one of the services perceived to be most needed by families of children and youth with special needs, with 44% of families reporting needing this service, but it was also the most unmet, with 80% of families reporting not having this need met (Kertoy et al., 2012).

In comparison to the above two studies, out of 38.9% of parents of adolescents and youth with borderline to moderate intellectual disabilities who reported needing respite care, only 39.9% of them had this need unmet (Douma et al., 2006). According to the 2002 New Zealand Household Disability Survey, only 7% of families of children with physical disability reported an unmet need for funding of respite care, which is less than other unmet needs (Clark & MacArthur, 2008).

Caregivers of children with more severe disabilities and behaviour problems reported higher levels of stress and reported more need for respite care (Chadwick et al., 2002). Based on this finding, the logical approach would be to allocate more respite care services to children with more severe impairment. However, a study by Larkin et al (2012) found that the mental health of caregivers is a function of the perception that their respite needs are being met rather than the actual amount of respite services they receive. Taken together, the results of these two studies imply that respite service provision should not be solely driven by impairment-based assessment but should also address the individual needs of families.

### 2.5.5 Need for care coordination

Care coordination is essential because families of children with disabilities usually receive services from multiple locations and systems with different entry points. Care which is not coordinated may result in duplication or unnecessary costs. Having the child's care coordinated can help reduce the number of places where the child has to go for services. Parental satisfaction with services was influenced by fewer places where services were received (Law et al., 2003).

Care coordination is a process that involves assessment, planning, implementation, evaluation, monitoring, support, education and advocacy occurring in multiple systems, with the goals of facilitating timely access to services, promoting continuity of care and enhancing child and family well-being (Lindeke, Leonard, Presler & Garwick, 2002). It involves facilitating communication between sub-specialty physicians with the general physician and other healthcare providers, connecting families with information and community resources, liaising with educational authorities to come up with an education plan tailored to the child, and guiding access to social supports. Care coordination is especially important at certain periods of time in a child's life, such as the first year after discharge from hospital, transition to school or to independent living, or at times of deteriorating health.

Comprehensive, coordinated care results in positive outcomes for the child and family. A programme intervention where CSHCN were provided coordinated care from primary care clinics with the services of a nurse practitioner was shown to reduce child school absences, utilization of ambulatory services, caregiver strain and parents' missed work days (Farmer, Clark, Sherman, Marien & Selva, 2005). Families also felt supported and were satisfied with the programme.

Care coordination through a medical home[1] and the availability of organized community services help reduce finance related problems in families of CSHCN (Kuhlthau, Hill, Yucel & Perrin, 2005; Ghandour, Perry, Kogan & Strickland). Families receiving care coordination had a lower risk of out-of-pocket expenditures and of problems in workforce participation (DeRigne, 2012). Having someone to help coordinate the child's care relieves the parent of the care burden of finding appropriate services so that they can pay more attention to work.

Care coordination is associated with fewer unmet needs and improved access to services and assistive devices (Witt, Kasper & Riley, 2003; Farmer et al., 2005; Kenney & Kogan, 2011; Boudreau et al., 2014). Families of children with higher illness burden and those with low coping resources benefit from coordinated care the most (Farmer et al., 2005). Families of children with cerebral palsy reported less needs when services are provided in a coordinated manner (Almasri et al., 2011). Disabled children with poor psychosocial adjustments were more likely to receive outpatient mental health services if their care was jointly coordinated by a family member and a health professional (Witt et al., 2003). Care coordination is associated with decreased unmet specialty care needs among CSHCN independent of household income (Boudreau et al., 2014).

Compared to receiving preventive medical care, there were higher rates of unmet needs in the areas of care coordination (Thyen et al., 2003); 2.3% did not have a doctor making arrangements for the child to see a specialist and 8.1% did not have their child's doctor communicating with kindergarten, school or child's therapists. Families of children with chronic health conditions had less access to and were less satisfied with care coordination services compared to other family support services (Farmer et al., 2004).

[1]The medical home is where medical services are delivered and directed by well-trained physicians in primary care

## 2.6 Access problems and barriers to care

Access problems can be defined as the difficulties experienced by families in the process of obtaining care. Barriers to care can disrupt the links in the processes of care, affecting health outcomes (Seid, Sobo, Gelhard & Varni, 2004).

In under-resourced settings, unavailability and inaccessibility of therapy services, as well as the supports that make them accessible, are the main reasons for unmet needs (Maulik & Darmstadt, 2007). Firstly, services may be unavailable, and even when they are, certain barriers cause problems with access.

Examples of difficulties experienced by families in the process of obtaining care are problems obtaining referrals, finding providers with skill or experience, getting enough visits and problems with the amount of money families had to pay. O'Neil, Costigan, Gracely and Wells (2009) found that 42% of CSHCN had at least one of the above access problems. In the 2000 – 2002 US National Survey of CSHCN, 22% of families with CSHCN who needed a referral had difficulty obtaining it (van Dyck et al., 2004).

The most common problems faced by CSHCN in obtaining needed care from specialty doctors include getting referrals and finding providers with appropriate training (Krauss, Gulley, Sciegaj & Wells, 2003). Higher financial burden caused by the child's condition and higher out-of-pocket expenses to pay for child's health needs were associated with increased risk of access problems to rehabilitation services (O'Neil et al., 2009).

Besides physical barriers to accessing services such as lack of parking space, waiting areas and consultation rooms which were not friendly for children with disabilities, parents identified non-physical barriers such as lack of flexibility of appointments and lack of understanding and knowledge of disabilities among health professionals, particularly around communication (Wharton, Hames & Milner, 2005).

Carers of children and youth with developmental disabilities and challenging behaviour reported problems accessing existing support services, such as facing delays and having to fight for or chase services, poor coordination, high staff turnover and communication problems with professionals (Wodehouse & McGill, 2009). Not receiving respectful and supportive care, lack of continuity and lack of care coordination were some of the elements often mentioned by parents who expressed dissatisfaction with paediatric rehabilitation services (King, Cathers, King & Rosenbaum, 2001).

Nesbitt, Mackey, Kuper, Muhit and Murthy (2012) grouped the commonly cited barriers in seeking and accessing care into 4 categories. *Logistics problems* are the cost of treatment or therapy, transport and distance problems as well as the opportunity cost involved when caregivers have to forego employment. *Beliefs* could be fear of treatment or a resigned attitude towards disability. *Socio-demographic factors* are the child and family characteristics which make accessing services easier or more difficult. *Specific factors related to disability or treatment* affecting access to care are age of onset of functional impairment, age of diagnosis of condition and cause of disability.

Seid et al. (2004) proposed five dimensions of Barriers to Care, which are skills, pragmatics, knowledge and beliefs, expectations and marginalization. *Skills* are a set of strategies to navigate the health care system while *pragmatics* refer to logistic and cost issues that may prevent or delay service utilization. *Knowledge and beliefs* include ideas about the nature and treatment of illness. *Expectations* refer to parental expectations of receiving poor quality care and *marginalization* refers to the internalization and personalization of negative experiences in the health care system. These dimensions are related to one another and families are likely to face more than one type of barrier when seeking care. Socio-demographic factors and specific factors related to disability or treatment influence skills, pragmatics, knowledge and beliefs.

For the purpose of this study, service barriers are grouped into socio-demographics, beliefs about disability and treatment, and service characteristics affecting access to care. Service characteristics relate to skills and resources, logistics and parent-provider relationship. *Skills* are a set of strategies to navigate the health care system (Seid et al., 2004) while *resources* refer to the availability of services and competency of service providers. Caregivers in rural areas especially, had poor knowledge about available services (Saloojee et al., 2007). Others have reported a scarcity of health care professionals who have the necessary skills and knowledge about treatment modalities and approaches in managing children with disabilities (McCarthy & Boyd, 2002; Wharton et al., 2005).

*Logistic* reasons for the low utilization of services include the cost of therapy, transport and distance problems, as well as the opportunity cost involved when caregivers have to forego employment (Nesbitt et al., 2012; Karaca-Mandic, Choi-Yoo, Lee & Scal, 2014). In addition, poor communication and bad experiences with service providers are problems in the *parent-provider relationship* which can affect parental engagement in the intervention process. The expectations and marginalization dimension in the Barriers to Care framework proposed by Seid et al occurs through contacts with health services.

### 2.6.1 Demographic and social structure factors affecting access to care

Family characteristics contributed most to explaining access problems, followed by child characteristics (O'Neil et al., 2009). Family characteristics include socio-demographic and family functioning characteristics. However, the focus here is on socio-demographic characteristics such as socioeconomic status, size of the family, marital status of the parents, parental age and health status of other family members. Socioeconomic status is conventionally measured by parental education, occupation and family income.

Child characteristics include child gender, child age, the manifestations of impairment of the chid and the child's behaviour. Impairment can be measured by the severity of motor and cognitive functioning, the extent of dependence for activities of daily living and any additional medical problems. Child's behaviour is assessed by issues such as conduct disorders, hyperactivity, emotional disorders and somatization.

#### 2.6.1.1 Factor predisposing to child's need for health care services

First, it is necessary to understand what influences the demand for services by looking at child and family characteristics which predispose to the need for certain services.

Parents whose child had more severe functional limitations were more likely to report a need for services (Porterfield & McBride, 2007) and children whose health condition was rated as more severe had a significantly higher mean number of needed services than those with mild health condition (Warfield & Gulley, 2006). Younger children were found to have more service needs (Warfield & Gulley, 2006; Porterfield & McBride, 2007).

Information about special needs plays a key role in seeking care – if parents do not think that their child needs a particular health care service, they will not seek access to that service. Higher income and more educated parents may have access to additional sources of information compared to lower income and less educated parents. As such, family income and caregiver's education level have been used as proxy measures of having information (Porterfield & McBride, 2007).

Mothers who did not complete high school were less likely to indicate their child needed specialist physician services, prescription medications and therapy services compared to mothers who had post high school education degrees (Porterfield & McBride, 2007). Parents of CSHCN whose family income was below the federal poverty level were less likely to indicate that their child needed specialist physician services and prescription medications but more likely to indicate that their child needed therapy services (Porterfield & McBride, 2007).[2]

Perceived need influences caregiver behaviour to seek and ultimately receive services for their child. CSHCN were very likely to get the specialist physician services and prescription medications that they needed if their parents identified them as needing it (Porterfield & McBride, 2007). However, they were less likely to obtain therapy services even if their parents indicated that therapy was needed.

Lower income and less educated parents generally have a lower perceived need for specialized health care services. But children of lower income and less educated parents did not necessarily have more unmet needs, depending on whether there were other problems affecting access to care.

[2] Federal poverty level is calculated from the combination of household income and the number of persons in a household.

#### 2.6.1.2 Factors predisposing to child's unmet need for health care services

Difficulties in access to care are reflected in the reporting of unmet needs. Findings on the effect of gender on unmet needs and access problems have shown that there is no difference between boys and girls (Mayer et al., 2004; Nesbitt et al., 2012).

Type of impairment affects access to care. Children with intellectual impairments were more likely not to have received therapy that they needed compared to children with physical or motor impairments. A Jamaican study found that 33% of children with gross motor disabilities and only 5% of children with cognitive disabilities had access to relevant services (Thorburn, Desai & Paul, 1992). Another study in a peri-urban South African township found that children with motor impairments were more likely to have received therapy than those with intellectual impairments, 44% vs 8% respectively (Saloojee et al., 2007).

Caregivers of children with a behavioural health condition were more likely to report at least one unmet service need, even after controlling for reported number of services needed (Warfield & Gulley, 2006). Children with autism spectrum disorder had more unmet needs for specific health care services, family support services and difficulty getting referrals than other CSHCN without emotional, developmental or behavioural problems (Krauss et al., 2003; Kogan et al., 2008).

Children with impairments in psychological functions or with emotional and behavioural health conditions are those expected to be in need of mental health services. Mental health services had higher access problems than other health care services, with 27.1% of those reporting need for mental health services having problems finding providers with skill/experience (Warfield & Gulley, 2006).

Type of impairment affected the uptake of referrals to rehabilitation and treatment services in a study conducted in two districts in Bangladesh (Nesbitt et al., 2012). The presence of epilepsy and physical impairment were associated with increased referral uptake, while visual impairment was associated with decreased referral uptake. Degree of visual impairment may help to explain this finding, but information on this was not available. Where epilepsy and physical impairment are obvious, mild visual impairment may not have a significant effect on the child's visual functioning, thus parents may be less motivated to seek services or assistive devices for the mild visually impaired child.

The majority of studies found that children whose condition or disability was more severe reported more unmet needs. Children who had poorer overall health status, less stability of health care needs and greater severity of their health condition were significantly related to greater unmet need in all types of services (Warfield & Gulley, 2006). The Canadian PALS found that caregivers of children with impairment of psychological functions who were severely limited in their everyday activities were much more likely to have unmet needs for child care programmes and health services, compared to those with less limitation (Baillargeon et al., 2011).

Families of young children with severe physical disability still experienced considerable unmet needs, particularly in the provision of information, despite frequent contact with multiple service providers (Sloper & Turner, 1992). This was especially so if their children also had mental retardation.

In the US, children whose functional ability was more severely affected by their condition were more likely to have an unmet need for specific care services and assistive devices (Dusing et al., 2004; van Dyck et al., 2004). CSHCN who were more severely affected by their condition were also more likely to report unmet dental care need (Lewis, 2002).

Children with multiple disabilities and with more severe disability in Taiwan were less likely to receive preventive health care (Tsai et al., 2012), but it is unclear whether they were also less likely to receive therapeutic medical care services. Among children with cerebral palsy, those with associated co-morbidities such as gastrointestinal and emotional problems had more unmet health care needs than those without (Jackson, Krishnaswami & McPheeters, 2011). Fewer health and development problems in the child was associated with higher parental satisfaction with services (Law et al., 2003; Ngui & Flores, 2006), which in turn contributes to lower expression of unmet needs.

O'Neil et al. (2009) found no association between severity of the child's condition with access to services. Although a ranking of severity of child's health status did not predict having access problems, more time spent by parents in providing home health care for the child did. Time spent in providing home health care can be used as a proxy indicator of the severity of the child's condition.

Children whose condition was ranked most severe were even found to be *less* likely to have an unmet need for specialty care compared to children whose severity was ranked mild to moderate (Mayer et al., 2004). Besides attributing the discrepancy in findings due to the different ways of measuring severity, the authors discussed the possibility that there is a threshold at which a child's condition is so severe that their parents either become adept at navigating the healthcare system or receive assistance with care coordination services. Parents may also have accepted the child's condition as unchangeable and feel that they do not need services. This belief may hold true in Asian communities where the concept of 'fate' is deeply ingrained.

Access to a medical home was significantly affected by severity of the child's condition in all socioeconomic strata (Fulda, Lykens, Bae & Singh, 2009). The greater the severity of the condition, the less likely the child received care in a medical home.

Older children had an increased risk of access problems to rehabilitation services (O'Neil et al., 2009) and higher perceived environmental barriers (Kertoy et al., 2012). Older CSHCN in their teens also had higher unmet needs for dental care (Lewis, 2002).

Race/ethnicity is often thought of as a marker variable for differences in access to and processes of care (Seid et al., 2004). Unmet needs associated with race/ethnicity are attributed to language barriers with service providers and cultural influences on perception of needs. They may also be present when there are significant discrepancies in education and income level between race/ethnicity groups.

CSHCN with non-English speaking parents in the US had more unmet needs for family support services, lack a personal doctor or nurse, lack a usual source of care and lack family-centred care (Yu, Nyman, Kogan, Huang & Schwalberg, 2004). At the same time, children with non-English speaking parents were actually more likely to come from less educated and lower income families.

Data from the US 1994 – 1995 National Health Interview Survey Disability Supplements showed that among disabled children with poor psychosocial adjustment, African American children were less likely to receive mental health services (Witt et al., 2003). Subsequently, the US National Survey of CSHCN in 2001 also found that among CSHCN with a chronic emotional, behavioural or developmental problem, African American children were more likely to have an unmet mental health need (Inkelas, Raghavan, Larson, Kuo & Ortega, 2007).

Parents of Hispanic children who could only communicate well in Spanish had higher unmet mental health needs (Inkelas et al., 2007), and the likelihood of Hispanic children experiencing access problems was reduced when language was controlled for (Yu et al., 2004). More Hispanic parents reported dissatisfaction with care and problems with ease

of service use than white parents, with the disparities found to be due to language barrier (Ngui & Flores, 2006).

In addition, more African American parents reported dissatisfaction with care and problems with ease of service use then white parents (Ngui & Flores, 2006). Lack of family-centred care in African American families was associated with the disparity in satisfaction with care. In a Dutch study, a higher proportion of children with severe mental disabilities belonging to an ethnic minority did not receive any routine dental care (De Jongh et al., 2008).

Other studies did not show ethnicity to be a health care access barrier. Child's ethnicity was not a predictor of access problems to rehabilitation services (O'Neil et al., 2009) and aboriginal status was not associated with usage of preventive health care services among children with disabilities in Taiwan (Tsai et al., 2012).

The relationship between ethnicity with barriers to care may depend on what dimension of barriers to care is being measured. In Seid et al's field test of their Barriers to Care Questionnaire (BCQ), they did not find a relationship between ethnicity with the total BCQ score. However, the relationship between ethnicity with each dimension was not elaborated. There is a possibility that ethnicity affects each of the dimensions differently, whereby different ethnicities may have different levels of skills, pragmatics, knowledge and beliefs, expectations and feelings of marginalization.

The association between parental education level and unmet needs varies, with some studies finding lower education associated with more unmet needs, others finding lower education associated with less unmet needs and some finding no association, depending on the type of service needs studied.

Porterfield and McBride (2007) found that children of mothers who did not complete high school were less likely to receive specialist physician services that they need, but more likely to receive therapy services and prescription medications. Mayer et al. (2004) found that there was no association between maternal education and having an unmet need for specialty care after controlling for other factors. But children of mothers with high school education were less likely to receive routine care compared to children of mothers with less than high school education.

Parents who had more than a high school education were more likely to report their child not receiving one or more needed services than parents with high school education or less (Warfield & Gulley, 2006). In another study, parental education level was not a predictor of access problems to rehabilitation services in children with special health care needs (O'Neil et al., 2009).

Poverty has been demonstrated to be a significant factor that affects access to care. Parents of CSHCN whose family income was below the federal poverty level were less likely to get the needed specialist physician services, prescription medications and therapy services compared to families earning >200% of the federal poverty level (Porterfield & McBride, 2007). Poverty was significantly associated with having an unmet need for both routine and specialty care (Mayer et al., 2004).

Families who were in or near poverty were more likely to report an unmet need for specific care services (van Dyck et al., 2004). CSHCN from poorer families were also more likely to have unmet needs for dental care (Lewis, 2002), as well as for vision and hearing care services and aids (Dusing et al., 2004). Where household incomes are low, it is difficult to justify spending on therapy when there is a lack of visible progress in the child's abilities and lack of obvious results following therapy.

O'Neil et al. (2009) did not find family income to be a predictor of access problems, but the risk of having access problems increases when families reported more financial hardship caused by the child's health condition and higher out-of-pocket expenses to pay for child's health needs. Level of unmet need among families of children with severe physical disability was higher in families where the fathers were more likely to be unemployed (Sloper & Turner, 1992).

Having siblings with special health care needs has been shown to be a protective factor against risk of access problems (O'Neil et al., 2009). Families with only two or more children with special health care needs were at lower risk of having access problems to rehabilitation services compared to families with only one special needs child. This finding suggests that parents may learn to navigate the health system more effectively when they have had experience in obtaining services for their other children. There is however, a lack of studies looking at the presence of another child with disability and caregivers' health status as factors affecting access to care.

Krauss et al. (2003) found that CSHCN whose parents were in poor health had problems obtaining needed care from specialty doctors. Besides taking care of the child with disability, caregivers with medical problems also have to take care of themselves, which may lead to the child having more unmet needs. But in another study, parent's health status did not predict having access problems to rehabilitation services (O'Neil et al., 2009).

Children who had higher number of services needed had higher prevalence of not receiving one or more of these services (Warfield & Gulley, 2006), indicating that those who have the most need may actually face the most problems in regards to access to care.

#### 2.6.1.3 Factors predisposing to family needs

Parents of children with multiple conditions indicated a greater number of family needs (Sloper & Turner, 1992; Perrin et al., 2000), particularly if their child had mental retardation as well as physical disability. Parents of children with spina bifida and cerebral palsy expressed more need for information on community services compared to parents of children with solely psychomotor retardation and disorders of motor control (Hendriks et al., 2000).

Regardless of diagnostic condition, parents who rated their child's condition as more severe indicated more needs (Perrin et al., 2000). In the US National Survey of Children with Special Health Care Needs, children whose functional ability was most severely affected by their condition were more likely to have an unmet need for family support services (van Dyck et al., 2004). The child's ability to independently perform activities of daily living is a determining factor of caregivers' perceptions of the need for personal care services (Fournier et al., 2010).

In a study using the Family Needs Survey, poorer child functioning was related to higher number of total family needs and was a significant predictor of information need (Farmer et al., 2004). But child functioning did not contribute significantly to the prediction of need for caregiver support, need for community services or need for help with family relationships or financial costs.

The greater the child's need for extra care (or in other words, the more dependant the child is on others), the greater the need for information on community services (Hendriks et al., 2000). Higher gross motor function level was associated with less family needs related to finding community and financial resources, and less child communication problems were associated with fewer family needs related to family functioning (Almasri et al., 2011).

Caregivers of children with impairment of psychological functions who were severely limited in their everyday activities were much more likely to need respite care compared to those with less limitation (Baillargeon et al., 2011). Respite care was desired by caregivers of children with more severe intellectual disability and behaviour problems, and caregivers who had higher levels of stress (Chadwick et al., 2002).

Japanese mothers and fathers of children with pervasive developmental disorders had more family needs than those with other diagnoses (Ueda et al., 2013). Children with pervasive developmental disorders suffer from delays in the development of basic skills, particularly the ability to socialize with others, to communicate and to use imagination. Children with autistic spectrum disorder are included in this group. Interestingly, among children with pervasive developmental disorders, there was no difference in mothers' needs by degree of disability. This means that regardless of the severity of the disability, families of these children already need more help in their caregiving role.

Better child adaptive behaviour in children with cerebral palsy was associated with fewer family needs for information and help explaining to others (Almasri et al., 2011), while more anxious and depressed behaviour in the child was related to more need for support and for help in explaining to others (Hendriks et al., 2000).

Parents of youths with intellectual disabilities reported needing a friendly ear, information, respite care, practical or material help and counselling more if their child had both emotional and behavioural problems compared to if their child only had emotional problems (Douma et al., 2006).

Caregivers of younger children expressed more needs compared to caregivers of older children (Ueda et al., 2013). Parents of younger children reported experiencing higher levels of burden (Tadema & Vlaskamp, 2009), which could account for them reporting more needs related to caregiving. In contrast, child's age was not a determinant of needs

in families of children with cerebral palsy (Almasri et al., 2011), possibly because these families may have ongoing needs which do not diminish or escalate with the age of the child. A higher level of perceived care burden in younger children could explain why caregivers of younger children with cerebral palsy were more likely to report higher unmet support needs than those with older children (Gordon, Lang, Larkin & Johnston, 2012).

As with unmet need for child specific services, differences in the expression of family needs among different ethnicity groups could be due to cultural influences on perception of needs or due to actual socioeconomic disparities causing access problems to family support services.

Families who were white reported fewer family needs than those from minority groups (Farmer et al., 2004). They were also more likely to perceive a higher quality of child and family services (Bailey et al., 2007). When perception of quality of services was adjusted for, non-white families reported less positive impact of services on the family. Latino families were more likely to cite unmet needs in rehabilitation programmes and need for more information or support group, while Euro-American families cited unmet needs in lack of day care, respite services, recreational programmes and home health aides (Gannotti, Kaplan, Handwerker & Groce, 2004).

Families who spoke a language other than English at home in the UK were less likely to indicate a need for respite care services (Chadwick et al., 2002). This was thought to be due to lack of awareness of services (in some cases due to language barrier) or that there is a perception in some cultures that it would be a disgrace to accept help from agencies outside the extended family.

Different studies have found different associations between socioeconomic status, measured by parental education, income or occupational level, with family needs. Akmese, Mutlu and Kayhan (2012) reported that mothers' perception of knowledge, support and general needs was affected by their education level. But Hendriks et al. (2000) did not find any association between parental education level and occupational level with family needs.

Douma et al. (2006) initially reported more support needs in parents with higher occupational level but these associations did not remain after adjustment for other child and family characteristics. Parents with higher educational level however did report more need for respite care, and as a consequence were considerably more likely to receive it (Douma et al., 2006).

Farmer et al. (2004) and Ueda et al. (2013) found a significant association between higher number of family needs with lower income. According to Almasri et al. (2011), family income was not associated with family needs for information and support but lower family income was associated with more needs for community services and financial needs.

Families who were in or near poverty were more likely to report having an unmet need for family support services (van Dyck et al., 2004). Poorer families reported less positive impact of family services, even after adjusting for race and child health status (Bailey et al., 2007).

Other socioeconomic factors such as living in rented accommodation and inadequate housing did not influence the desire for respite care (Chadwick et al., 2002). In another European study, high levels of unmet social and educational support needs in parents of children with severe disabilities were not associated with socioeconomic deprivation (Forsyth et al., 2010). Again, we see that the association between socioeconomic status

and different aspects of family needs varies with the perception of need and the accessibility of services.

Other child and family characteristics predisposing to family needs have been studied. Marital status of the parents was not related to family needs (Hendriks et al., 2000; Douma et al., 2006). Family needs were also neither related to parental age (Hendriks et al., 2000) nor to child gender (Douma et al., 2006). Number of children in the family was not found to be related to caregiver needs (Hendriks et al., 2000; Douma et al., 2006) or parental stress (Chadwick et al., 2002). Japanese mothers who had more than one child with a disability were more likely to indicate needs for family and social support (Ueda et al., 2013).

### 2.6.2 Beliefs about disability and treatment

Different beliefs and attitudes towards disability and treatment can become access problems. Firstly, strong cultural beliefs in certain communities, especially in rural areas, still pose a barrier for families to bring their disabled child for services (Pongprapai et al., 1996; Gona, Mung'ala-Odera, Newton & Hartley, 2010). In Africa, disability is still perceived as a curse, punishment from God for wrong doing, or the work of evil spirits, which has resulted in parents hiding their children with disabilities for fear of segregation or discrimination (Gona et al., 2010). A lot of time and money is spent on seeking a cure (Hartley, Ojwang, Baguwemu, Ddamulira & Chavuta, 2005), often unattainable and diverting family resources from seeking rehabilitation services.

Caregivers' perceptions that the child would not be able to cope or that the severely disabled child "could not do anything" were cited as reasons for not utilizing services in a peri-urban South African township (Saloojee et al., 2007).

Families of autistic children received less financial assistance than families of physically disabled children (Xiong et al., 2011). This disparity was attributed to parents not wanting their autistic child to be certified disabled, hence hindering them from acquiring financial assistance in Beijing, where disability certification was a pre-requisite.

Secondly, priority assigned to certain health care services affects the demand and supply of those services. Oral health is often not considered a priority issue for children with disabilities by both caregivers and health care providers. Oral health care assessment was not on the agenda of medical health professionals (Hallberg & Klingberg, 2005) and neither caregivers nor medical or dental health professionals seemed to take an overriding responsibility for the oral health of children with disabilities (Klingberg & Hallberg, 2012). Low priority for dental care among caregivers of children with epilepsy and fear of dental care among children with cerebral palsy were major barriers to dental care (Aburahma, 2011).

Thirdly, different attitudes between caregivers and service providers may impact on the therapeutic process. Social barriers faced by therapists in prescribing augmentative and alternative communication devices include the readiness of the child and family to use a device (their acceptance, attitudes and view towards the technology), and how much priority the family placed on the child's ability to perform certain functions (Lindsay, 2010).

Parents and service providers sometimes have different expectations towards therapy (Kovanen, 2001; Lindsay, 2010). For example, parents of children receiving speech therapy perceived improvements in speech clarity to be more important than improvements in communication skills (Carroll, 2010). Service providers need to explore parents' expectations and establish joint realistic goals with parents.

Parents want to be more aware, but do not necessarily want to be more involved, in their child's therapy (Carroll, 2010). Parents regard health professionals as the experts on their child and expect health professionals to make decisions and carry out interventions. The perception that the burden of therapy lies only on the therapist calls for a clarification of roles and responsibilities between parent and therapist (Carroll, 2010).

### 2.6.3 Service characteristics affecting access to care

The way services are organized is crucial in determining access to services. Many challenges faced by caregivers of children with disabilities are due to a lack of necessary environmental supports. Insufficient resources for services, financial barriers and service fragmentation are some of the service characteristics affecting access to care.

#### 2.6.3.1 Skills and resources

The literature shows that parents have unmet needs for information, guidance, understanding and support. Families may be ignorant about services available for their children, thus rendering their potential access to care lower. Parents also face difficulties in attaining the skills needed to advocate for their child and to navigate the complex service delivery system.

Caregivers had poor awareness about the right to health care and poor knowledge about available services (Thorburn et al., 1992; Pongprapai et al., 1996; Saloojee et al., 2007). The need for increased awareness of the rights of their children and better understanding of their children's problems by the community were some of the needs identified by parents (McConkey, Truesdale-Kennedy, Chang, Jarrah & Shukri, 2006).

One of the main reasons parents of youths with intellectual disabilities and emotional/behavioural problems did not seek support was that they did not know where to find the support that they needed such as information, activities for the child, respite care, practical or material help, child mental health care and parental counselling (Douma et al., 2006).

Service barriers primarily identified by caregivers of children with developmental disabilities were 'lack of information' and 'lack of available services' (Betz et al., 2004; Wodehouse & McGill, 2009). Lack of resources at school is one of the reasons why school aged children with special health care needs could not access needed therapy services. In addition, service providers did not provide families with enough information about available services. Families even perceived service providers to lack the knowledge about available resources and did not respond adequately to their concerns (Betz et al., 2004).

Problems encountered in support provision for specific challenging behaviour among youth with developmental disabilities include ineffective strategies being suggested, lack of expertise regarding behaviour management and insufficient specialist services such as providing parent training and emotional support (Wodehouse & McGill, 2009).

There is a scarcity of health care professionals who have the necessary skills and knowledge about treatment modalities and approaches as their training curriculum does not emphasize content or practical experience in managing children with disabilities. Providers also lack the motivation to manage these children as it is perceived to be time consuming without immediately recognizable benefits.

The development of mental health services for people with psychiatric and behaviour disorders have been poor due to lack of recognition at the primary care level and insufficient numbers of trained mental health professionals (McCarthy & Boyd, 2002).

Two major areas for improvement are the need for improved organization of services and care coordination, and the need for better-trained service providers to comprehensively assess and respond appropriately to the needs of children with disabilities and their families (Betz et al., 2004).

Poor knowledge about the importance of oral health and limited ability to assess and treat oral health problems in disabled children were reasons for poor access (Oredugba & Sanu, 2006; Klingberg & Hallberg, 2012). Only 19.3% of dentists in a Nigerian study rated their knowledge of management of children with special needs as adequate, and only 12.8% rated their undergraduate training on this topic as adequate (Oredugba & Sanu, 2006). Dentists found the treatment of oral health problems in children with special needs as challenging. Communication problem with children with severe mental disabilities was considered by dentists as the most important barrier in providing them with dental treatment (De Jongh et al., 2008).

Barriers to receiving nutrition services identified in children with special health care needs were lack of screening tools specific to the population, lack of primary care provider knowledge or experience, lack of awareness among providers or parents on nutrition, poor collaboration/coordination among providers, cumbersome referral processes and shortage of trained or experienced nutritionists (Bujold, Swan & Taylor Baer, 1998).

In order for the child with disability to acquire equipment that overcomes his/her limitations, the need for assistive technology has to be assessed by a competent health care provider, taking into account family or caregiver perspectives (Ried et al., 1995). However, therapists faced technical challenges, social, financial and organizational constraints in prescribing assistive technology and home adaptations (Roy, Roussea, Allard, Feldman & Majnemer, 2008; Lindsay, 2010).

Speech language pathologists and occupational therapists expressed technical challenges involving the complexity of devices as influencing their decision to prescribe augmentative and alternative communication (AAC) devices for children with disabilities (Lindsay, 2010). Organizational problems identified were shortage of qualified therapists, a complex prescription review process, inconsistent follow-up procedures, limitations in the consultation process, and gaps in policy.

Paediatric physical therapists reported having less than adequate training in assistive technology (AT) and lack of confidence in delivering AT services (Long & Perry, 2008). They would like training that focuses on assessment and evaluation methods, knowledge of specific devices, and knowledge on funding of the technology.

#### 2.6.3.2 Logistics, including cost

Even if caregivers knew services are available, they may not be able to afford those services or lack the social support to actually utilize those services (realized access). The structural element of paediatric rehabilitation service delivery, particularly lack of access to existing services, is often mentioned as a cause of parental dissatisfaction (King et al., 2001).

Financial difficulty is one of the main reasons for low utilization of services (Thorburn et al., 1992; Pongprapai et al., 1996), and access is made worse by bureaucratic and administrative obstacles. It is no wonder then that caregivers with limited capacities may just “accept” the way things are and leave things be, causing unnecessary care burden later on.

The main barriers to uptake of referrals in rural areas are commonly attributed to long distances and lack of available transport. To overcome this, the community based rehabilitation centre (CBR) concept, built on local knowledge and practices, has been widely advocated. The challenge of the CBR concept is to have adequate staff, equipment and skills in rural health centres which can cater to children with disabilities. Most if not all of the time, these rural health centres function as primary health care centres (PHCs) which serve the community at large. PHC workers attend to patients of all ages and a wide range of health problems. The primary health care unit is usually inadequate to provide appropriate care to children of disabilities, so the responsibility of rehabilitation depends heavily on the family unit who may be incapacitated by poverty.

Making services available to children with disabilities in low and middle income countries does not guarantee their use (Magnussen, 2011; Nesbitt et al., 2012) if the supports that make them easily accessible are lacking. Children with disabilities in rural Zambia are frequently referred to higher level health facilities, but families find it difficult to follow through with the referrals (Magnussen, 2011).

Lack of adequate means of transport for children with disabilities, especially in rural areas, impede their ability to utilise rehabilitation services in health facilities, CBR centres and to attend schools which can provide the most suitable education to them. McConachie et al. (2001) found that the cost of travel hindered mothers who stayed far from the centres from accessing services.

Another factor which affected the use of services was the cost of the service itself. Therapists prescribing augmentative and alternative communication devices reported the families' financial ability, and gaps in funding as barriers to the procurement of those devices (Lindsay, 2010).

Different financing arrangements affect the delivery of services. Health insurance plans have an incentive to minimize the use of services to control cost. Some health insurance plans only assign patient to primary care providers and do not provide for referrals to subspecialists (Perrin, 2002; DeRigne, 2012). In addition, access to certain specialized therapies was limited by the inability to show child improvements in the short term. In the US, the payment for assistive devices was difficult to obtain even for those with Medicaid insurance because Medicaid allows replacements only infrequently and children often outgrow their equipment well before the authorized replacement time.

The two most common reasons for CSHCN not getting referrals that they needed were that the services "cost too much" and there was a "health plan/insurance problem" (van Dyck et al., 2004). Families with no insurance were more likely to report an unmet need for services (Mayer et al., 2004; van Dyck et al., 2004; Warfield & Gulley, 2006). Public and private insurance appeared equally effective at providing access to specialist physician services and prescription medications, but equally ineffective at providing access to therapy services (Porterfield & McBride, 2007).

Before the enactment of the US Health Care and Education Reconciliation Act and federal Mental Health and Substance Abuse Parity law, private health insurance plans did not offer benefits for mental health conditions on par with those provided for physical health conditions (DeRigne, 2012). During this period, primary care physicians reported dissatisfaction with the availability of mental health services (Davidson, 2002).

The difference in uptake of referrals to rehabilitation and treatment services in two districts (one urban and one rural) in Bangladesh could be explained by the way services were provided in those districts (Nesbitt et al., 2012). In the urban district, a local NGO provided therapy for children with cerebral palsy in their homes. This district showed

higher uptake for all types of referrals except assistive devices. In the other district, assistive devices were provided directly by a local NGO. Higher monthly income was associated with increased referral uptake in the rural district. In this district, families were not routinely provided with transportation and were asked to pay a nominal fee for services if they could afford it.

In the urban district, costs were covered equally for all families and a system of organizing transport and accompaniment to more distant service centres was set up. In this district, instead of monthly income, maternal literacy became a predictive factor of referral uptake. It is possible that provision of financial and logistic support to families mitigated the effect of income on referral uptake. Hence, mothers' knowledge to follow through with the supports in place became the decisive factor.

In Taiwan, since the introduction of the National Health Insurance in 1995, free preventive child health care services, which consist of physical examinations and health education, are provided to all children below the age of 7. Preventive health care usage among children with disabilities was found to decrease with level of urbanization (Tsai et al., 2012). This contradicted with the findings of previous studies which showed lower utilization of health services in rural areas due to poor access to care. The authors of this study proposed that improved access to health care in rural areas may have been due to the implementation of mobile health services providing screening and vaccination which are funded by the Plan of Medical Network in Taiwan.

The above examples illustrate that service delivery, and subsequently service receipt, is affected by how services are funded.

#### 2.6.3.3 Parent-provider relationship

Parent-provider relationship is an important factor explaining parents' satisfaction with paediatric rehabilitation services (King et al., 2001; Jansen, van der Putten & Vlaskamp, 2013). However, even if family support services are provided, they may be unhelpful depending on the quality of the service and the nature of the parent-provider relationship.

McConkey et al. (2006) found that the number of contacts mothers had with professionals did not impact on the well-being of mothers of children with intellectual disabilities. It was felt that professionals looked 'down' on parents, thinking they are the experts and that parents should do everything they say (McConkey et al., 2006). On the other hand, health care providers are led to assume parents as being 'passive' when parents do not appear to involve themselves in joint multidisciplinary team meetings, when in fact this was because parents could not assimilate all the information shared in the meeting (Kovanen, 2001).

Hospital staff underestimated carers' emotional distress and need for information, and carers indicated that the reception they got in health facilities were not to their expectations (Gona et al., 2010). Parents found health providers to be a source of comfort and reassurance when they can provide anticipatory guidance and understood their challenges (Kratz, Uding, Trahms, Villareale & Kieckhefer, 2009).

Information exchange and communication between caregivers and health care providers are important elements for improved care coordination (O'Neil, Ideishi, Nixon-Cave & Kohrt, 2008) and building family competencies (Washington & Schwartz, 1996). They are what parents of a disabled child want from a health professional (Carroll, 2010; Fereday, Oster & Darbyshire, 2010).

Among the issues identified in children's rehabilitation, therapy programmes that do not overburden children and families are one of them (Gibson et al., 2009). The importance of understanding family preferences and priorities is also emphasized in the use and prescribing of assistive technology for children with disabilities. Parental involvement and engagement in the intervention process and consideration of the demands that interventions place on families are highlighted in the literature (Ried et al., 1995; King, Batorowicz & Shepherd, 2008; Roy et al., 2008).

Parent-provider relationship is one of the key elements of 'family-centred care'. Family-centred care is widely endorsed as a best-practice model in paediatric rehabilitation (King et al., 1999; Kuhlthau, Bloom, et al., 2005; Dickens, Matthews & Thompson, 2011). Family-centred care means providing resources, supports and services in response to family identified needs and priorities (Almasri et al., 2011). Children and families should have the opportunity to decide the level of involvement they wish in decision-making about services, children and families should be treated with respect, the needs of all family members should be considered and the involvement of all family members should be supported and encouraged (King et al., 1999; Gibson et al., 2009).

A family-centred approach is associated with better access to services, and in turn, better access to services is associated with less family needs. Parents who perceived services as more family-centred had fewer family needs related to community and financial resources and fewer family needs related to family functioning (Almasri et al., 2011).

Qualitative data suggests that a family-centred, strengths-based approach which supports family's social and emotional needs is effective in empowering families of children with disabilities (O'Neil et al., 2008; Samuel et al., 2012).

## 2.7 Care burden

Unmet medical care and psychological needs are associated with increased family burden. After controlling for socio-demographic factors, unmet medical care needs and psychological needs resulted in significant additional effects on family burden, above and beyond the complexity of disability in the child and nursing care load (Thyen et al., 2003). Higher number of family needs was also associated with greater perception of family burden (Farmer et al., 2004). Addressing unmet health needs may alleviate the impact of caring for a child with a disability.

Factors which influence caregiving burden are the background of the family, child characteristics, caregiver strain/stress, intra-psychic factors and coping factors (Raina et al., 2004).

Background addresses the setting in which caregiving takes place, with emphasis on the socioeconomic characteristics of the family. Disability is associated with disadvantaged socioeconomic conditions, creating additional risk of adverse health outcomes.

Compared to children without disabilities, children with disabilities tend to come from less-educated, lower income and single parent families (Park, Glidden & Shin, 2009; Houtrow A.J. et al., 2011). They were also more likely to live in a household where another member (adult or child) had a disability (Shandra, Avery, Hogan & Msall, 2012). In addition, households where there were multiple members with disability were more likely to experience poverty, inadequate housing, low adult education and adult unemployment (Shandra et al., 2012).

Child characteristics include the manifestations of the child's impairment and the child's behaviour. Perceived intensity of child behaviour problems was found to contribute significantly in explaining family quality of life in families of young children with developmental disabilities (Davis & Gavidia-Payne, 2009).

The daily demands on the caregiver and the conflict between the caregiving role and occupational role produces caregiver strain. Receipt of help from support sources can alleviate caregiver strain to some extent.

Intra-psychic factors refer to the caregiver's self-perception, indicated by measures of caregiver's self-esteem and sense of mastery over the caregiving situation. A comparison between mothers of children with disability and without disability revealed that the disability status of the child plays an influential role in explaining mother's sense of competence and role restriction (Park et al., 2009). If the child is disabled, mothers tend to worry more about raising their child. Mothers of a child with disability had a lower sense of competence even after controlling for their education and income status (Park et al., 2009).

In the early childhood period, parenting stress is determined by aspects of the family environment such as income, family cohesion and family support (Warfield, Krauss, Hauser-Cram, Upshur & Shonkoff, 1999). Lower education and higher income is associated with a higher sense of competence in mothers of a child with disability (Park et al., 2009). Mothers with higher education may be self-critical of handling their child when they experience challenging issues and feel that they have failed to perform their duties as a good parent compared to mothers with lower education. Parental mental health has been shown to be negatively affected by low income and dysfunctional parent-child interaction (Hung, Wu, Chiang, Wu & Yeh, 2010).

Social support, family function and stress management are factors which help caregivers cope. Social support is derived from the social relationships of the caregiver with the extended family, friends and other members of the community. Family functioning measures the extent to which a family works as a unit, and stress management measures the strategies and practices of the caregiver in response to problematic situations.

Better family demographic factors such as better socioeconomic status, lower levels of child disability and protective social-ecological factors such as family functioning and level of social support are predictors of less care burden (King et al., 1999).

### 2.7.1 Financial impact

Raising a child with disability involves elevated costs of obtaining services and child care, difficulty balancing parental employment with caregiving responsibilities and inadequate leave time for parents to attend to their child's episodic care needs (Parish & Cloud, 2006).

The medical and child care costs of children with disabilities are higher than for children without disabilities (Xiong et al., 2011). Caregivers, especially mothers, are frequently unable to work outside the home because of caregiving responsibilities. This brings the family income to a lower level than that of families of non-disabled children, even when welfare benefits are included.

Children with special health care needs use more services than children without special health care needs (Newacheck, Inkelas & Kim, 2004; Swanson, Wall, Kisker & Peterson, 2011). CSHCN had more hospital days, non-physician professional visits and home health provider days. CSHCN also had double the amount of physician visits and five times the amount of non-physician visits.

Compared to children without special health care needs, total health care expenditure for CSHCN, which included expenditures for hospital inpatient and outpatient services, physician services, dental services, services provided by health care professionals other than physicians, prescribed medications, diagnostic tests and certain types of medical equipment and supplies, was higher (Newacheck et al., 2004). Average total health

expenditure for CSHCN was four times the average for children without special health care needs, corresponding to their higher use of services.

Out-of-pocket (OOP) expenditure for CSHCN was also higher. Even though families paid a smaller percentage of health care bills (about 11%) out of pocket for a child with SHCN compared to about 28% for a child without SHCN, the absolute out-of-pocket expenses are higher in CSHCN (Newacheck et al., 2004). Average OOP expenditure for CSHCN was about 50% higher than the average for children without SHCN.

The financial impact of raising a child with disability or special health care needs can be summarized into impact on family out-of-pocket expenditure and impact on family employment.

In the NSCSHCN 2000 – 2002, 21% of respondents reported that the family had financial problems because of the child's condition and almost 30% reported that at least one family member had to reduce or stop work because of the child's condition (van Dyck et al., 2004).

Kuhlthau, Hill, et al. (2005) studied the financial burden for families of CSHCN by looking at four finance-related family outcomes; 20.9% of the respondents said that the child's health care had created financial problems, 27.7% said family members have had to cut work hours to care for the child, 18% needed additional income for the child's medical expenses and 13.2% said a family member has had to stop work due to the child's health.

According to the second NSCSHCN 2005 - 2006, over 40% of family members of children with Down syndrome or other mental retardation/developmental delay stopped working because of the child's condition and about 40% reported the child's condition caused financial problems (Schieve, Boulet, Kogan, Van Naarden-Braun & Boyle, 2011).

The Australian Institute of Health and Welfare report on children with disabilities found that 34% of families felt they needed financial assistance and 62% of mothers were unemployed (2006). Unemployment further adds to the financial strain already faced by families dealing with the extra costs of raising a disabled child. The risk of financial burden was higher when parents had to reduce or stop work (DeRigne, 2012).

Most mothers of children with disabilities wanted and needed to work for pay but were prevented from work participation mainly due to service system limitations (Bourke-Taylor, Cotter & Stephan, 2014). Besides reducing financial burden, employment is important because it helps parents build resilience (Murphy, Christian, Caplin & Young, 2007). Service system limitations faced by mothers include difficulty finding appropriate skilled carers and unavailability of outside-hours school care (Bourke-Taylor et al., 2014). These mothers reported poorer health and lower family income compared to other working Australians, despite having higher education.

The Canadian Participation and Activity Limitation Survey 2001 reported that 43.2% of caregivers who had children with impaired psychological functioning did not take a job in order to take care of their child, 28.4% had to quit working and 49% worked fewer hours (Baillargeon et al., 2011). In a study of disabled children recruited from a children's hospital in Germany, 23.1% of mothers stated they had quit a job because of the child's disability (Thyen et al., 2003).

From a macro or national perspective, greater child service needs is associated with higher costs of health, education and social care services. Increased severity of disability, greater number of behavioural problems and younger child age (all contributing to greater service needs) are associated with higher costs of health, education and social care services (Beecham, Chadwick, Fidan & Bernard, 2002).

#### 2.7.1.1 Factors associated with financial and employment problems

Poverty level, parental education level, race/ethnicity, age of the child, type and severity of child's condition are some of the child and family factors which have been studied for its association with financial burden and employment problems faced by families of children with disabilities. Studies in the US also frequently look at the role of insurance and the medical home in moderating these impacts.

Low-income families experience heavier financial burdens when measured relative to their ability to pay. Compared with households with incomes>400% the federal poverty level, children in households <200% FPL spent 172% more of their family income on health care for their child with disability (Newacheck et al., 2004). They were also 19 times more likely to experience catastrophic expenditure.

Poorer families were more likely to have their child's condition causing financial problems, family members having to reduce work hours or stop work because of the child's condition, and needing additional income for the child's medical expenses (van Dyck et al., 2004; Kuhlthau, Hill, et al., 2005).

However, financial impacts can be mediated by parental education level. Better parental education increases the odds of parental employment (Rupp & Resslerb, 2009). Mothers with lower education were less likely to report a finance-related problem (Kuhlthau, Hill, et al., 2005), indicating that education level does play a role in influencing parental perception of facing financial hardship.

Race/ethnicity was not found to be associated with having finance-related problems but having younger children with special health care needs was (Kuhlthau, Hill, et al., 2005). The odds of having a finance-related problem increased by 81% if the respondents had a child with special health care needs aged 0-5 compared to a child aged 13 – 17, and increased by 17% if the child was aged 6 – 12.

More severe child condition increases the likelihood of the family having finance-related problems (Loprest & Davidoff, 2004; van Dyck et al., 2004; Kuhlthau, Hill, et al., 2005). Caregivers of children who had more severe functional limitations were more likely to face restrictions in work force participation (Baillargeon et al., 2011; Schieve et al., 2011) and greater out-of-pocket medical costs (DeRigne, 2012). Mothers of children with a secondary disability were more likely to be unemployed than those without a secondary disability (Wei & Yu, 2012).

Type of condition also affects families financially. Compared to CSHCN in general, a greater proportion of families of CSHCN with emotional or behavioural difficulties experienced financial problems and changes in family member employment (Ghandour et al., 2010). Families of children with autism in China had the heaviest financial burden, followed by families of children with physical disability and mental disability (Xiong et al., 2011). The higher financial burden was due to higher cost for rehabilitation and education. Families of children with autism spectrum disorders were more likely to report financial problems, need additional income for the child's medical care, and had higher OOP expenditure compared to families of children with special health care needs without emotional, developmental or behavioural problems (Kogan et al., 2008; DeRigne, 2012). Family members were also more likely to cut work hours or to stop work altogether because of the child's condition.

Health insurance offered protection against financial burden, whereby families with an insured child spent 51% less of their income on health care for their disabled child compared to families whose child was without insurance (Newacheck et al., 2004). Insured children had lower OOP expenditures than non-insured children, while children covered by public insurance had lower OOP expenditure than children covered by private health insurance (DeRigne, 2012). Having no insurance was also related to the child's condition causing financial problems (van Dyck et al., 2004).

### 2.7.2 Family well-being

With technological advancement, more and more children who otherwise would have died are surviving, but with varying degrees of disability (Perrin, 2002). Parents are suddenly handed the role of caregiving for a child with disability, a role which they never expected and most definitely, were not prepared for. Some parents adapt well to the new role, but some do not, putting them at risk of poor physical and mental health outcomes.

Parents of children with special health care needs face many challenges in coping with the demands and needs of their child. In addition to their typical parenting roles, parents also assume the role of care coordinator, medical expert, systems advocate and representative for their child. Challenges faced by parents include finding time for personal needs, social isolation, strained relationships, balancing child's need with siblings' needs, and ongoing frustrations with health care and education systems (Kratz et al., 2009).

Stressors in the context of caregiving are defined as the demands and obstacles that exceed or push to the limit the caregiver's capacity to adapt (Raina et al., 2004). Stress originates at an intersection between one's external environment and internal state, or when the demands imposed by the child's condition overwhelm the caregiver's perception on his/her ability to respond (Pearlin, 1989).

Primary stressors are those directly related to the individual and the disability, while secondary stressors are those arising from the demands of the caregiving role itself. Parents ranked finances as their number one source of stress (McAdoo, Younge, Hughes, Hanshaw & Murray, 2003). Other stressors were parenting, housing and work related.

Family socioeconomic status impacts on the stressful experiences of families living with disability. Poverty exacerbates the difficulties that families experience, while caregivers with lower education may not have the cognitive strategies to cope with the demanding situations of raising their children. Families with lower income reported a lower sense of competence and higher role restriction in raising their child with disability (Bailey et al., 2007; Park et al., 2009).

Parents of children with disabilities are likely to experience poorer physical, psychological and emotional health. Parents raising a child with disability experience more stress than those raising a child without disability (Park et al., 2009). There are increased daily demands associated with caring for a child with disability which take away time for mothers to take care of themselves (Raina et al., 2004).

Caregivers of children with disabilities reported their health worsening as a consequence of long-term, informal caregiving (Murphy et al., 2007). The negative impact on their health was attributed to a lack of time, a lack of control and decreased psychosocial energy. When parents experience poor health, they may be less able to care for their children, predisposing to negative outcomes for all family members.

Caring for a child with moderate to severe physical disability requires more physical work. These children have mobility impairments which require caregivers to carry the child from one place to another, or use physical strength to position the child for daily activities. Physical health problems in caregivers may be more prominent in low-income countries where families struggle with poverty, limited public services and lack of assistive devices. Caregivers of children with physical disability in Kenya have been reported to commonly suffer from chronic back pain (Geere et al., 2013).

The degree of child disability increases the potential for health problems in the caregiver. Parents of children with physical disability had poorer mental health if their child had poorer walking ability and higher dependency on others to perform activities of daily living (Hung et al., 2010). Other child characteristics which impact on caregiver's health include the amount of assistance the child needed, care over a long duration and the number of adjustments to daily life to accommodate the child (Goddard et al., 2008).

Child behaviour has been shown to be a predictor of family well-being. Parenting stress is higher among children with disabilities who have behavioural problems and lower levels of communication ability (Raina et al., 2004; Norizan & Khadijah, 2010). Parents of children with emotional problems were more likely to get divorced than children with only learning disabilities (Wei & Yu, 2012).

Younger age of the child is also associated with poorer parental mental health as parents are just starting to adapt to the role of caregiving for a child with disability (Hung et al., 2010; Gordon et al., 2012).

However, for children with severe disabilities, care needs have not been found to increase or decrease with advancing age (Curran, Sharples, White & Knapp, 2001), reflecting that this group of children had ongoing needs which account for a high level of care burden. Curran et al showed that time costs measured by frequency of care did not differ with age for these children, but only differed by degree of disability.

#### 2.7.2.1 Caregivers' coping and support systems

Caregiving may not necessarily be seen as a burden by the caregiver (Green, 2007) if they have adapted well to their caregiving role. The ability to see beyond the burden to the benefits of the caregiving role can reduce parental distress. In fact, caregivers may derive a sense of content and fulfilment from caring for their child with disability. There are studies where caregivers have reported positive contributions to their life as a result of caring for a child with disability (Geere et al., 2013; Lakhani, Gavino & Yousafzai, 2013).

Parents cope well by re-evaluating their initial perceptions of their child's disability and learning to value their child's potential (Falkenbach, Drexsler & Werler, 2008). Helpful strategies identified among parents were reframing one's perspectives and adjusting expectations, being prepared and knowledgeable about their child's condition, connecting with peers, becoming an advocate, developing partnerships with professionals and caring for one's self (Kratz et al., 2009).

Common coping mechanisms applied by carers of children with disabilities in poor rural settings were engaging in spiritual beliefs, sharing of experiences, learning new skills and looking for external support (Gona et al., 2010). Talking with a friend or relative and seeking religious help were common coping behaviours of African American and Mexican American parents of children with special needs when they felt stressed (McAdoo et al., 2003).

Mothers have expressed that care burden is a matter of socio-structural constraints (Green, 2007). Negative caregiver well-being occurs when there is a lack of match between caregiver needs and the services, resources or supports available in the community to meet those needs.

The more families experience social isolation, the more needs they had (Hendriks et al., 2000). Parents require continuing reinforcement of their self-esteem to help them in the process of raising their child with disability (Falkenbach et al., 2008) and they perceived lower care burden when they felt more supported (Tadema & Vlaskamp, 2009).

Stronger family relationships characterised by more cohesion, expressiveness and less conflict (Almasri et al., 2011), as well as higher perceptions of social support (Farmer et al., 2004) were associated with fewer family needs. In fact, parents' perceptions of the caregiving process and the social support they received were better predictors of family well-being than demographic characteristics of the family (King et al., 1999).

The stress process can be moderated by social supports and concepts of mastery or self-efficacy (Raina et al., 2004). To some extent, this explains how people who are exposed to the same stressors are impacted differently. In Hill's ABC-X Model of Stress (Boss, 2002), the direct relationship between A factors (the stressors) and X (the outcome of parenting stress) are buffered by B factors (coping resources) and C factors (perception of stressors and coping resources).

Stress in parents of children with Down syndrome and behavioural problems was modified by positive coping styles and parental psychological well-being (Norizan & Khadijah, 2010). A positive relationship between family and community support with parental confidence and optimism in the family's future is seen above and beyond the effects of child's health status, race, poverty or caregiver education level (Bailey et al., 2007).

Social support is important to families in order to reduce coping demands and mitigate their stress. Regardless of the difficulty of their circumstances, caregivers with high social support managed better compared to those with low social support. Caregivers of children with cerebral palsy who received adequate social support reported lower stress,

depression and anxiety compared to caregivers with unmet support needs (Gordon et al., 2012).

In this regard, family support services are seen to be equally important as child specific services. They serve to enhance social support by linking families with each other or with other community resources, and to help families cope with challenges.

Social support is a multidimensional construct referring to the assistance an individual receives from others (Park et al., 2009). Social support can be categorized into structural/functional support and formal/informal support.

The structural aspect of social support is concerned with the availability of different sources of support while the functional aspect refers to the types of activities involved in providing support. Functional support encompasses material aid, practical help with the child (playing with children, feeding and washing them, helping them to study), practical help for the family (help with housework), informational (giving advice on family matters and where to seek professional services), emotional support (offering comfort and encouragement, spiritual support, sharing concerns) and professional work (training or teaching children, assessing and treating them medically, referring children and families to relevant agencies) (Park et al., 2009).

Formal support is defined as help that is based on a fee or operated through funded services provided by professionals, while informal support is help or services that is not paid for. Formal support comes from health care workers, teachers, social workers or agencies, while informal support comes from immediate or extended family, friends, neighbours, other parents of children with disabilities, local community groups and religious organizations.

Formal support was rated to be more important than informal support among Malaysian families (Clark et al., 2012) and Dutch families (Tadema & Vlaskamp, 2009). Nevertheless, both formal and informal supports are important for family adaptation but likely operate in different ways with different effects (Bailey et al., 2007).

Different sources of support play different roles in the functional aspect of social support, and one source may play more than one role in varying degrees. Health care and social workers are better at providing information and support related to their professional work, while practical help and emotional support are best performed by family and friends. Fathers may contribute more in terms of material aid and less in terms of emotional support.

In a Malaysian study on children attending community based rehabilitation centres, need for support from a teacher or therapist was endorsed by 75.3% of caregivers, from family members by 63.2%, and from friends by 69.1% (Suriati et al., 2011). In Japan, need for support from a teacher or therapist was endorsed by 43.7% of mothers, from family members by 27.8%, and from friends by 25.1% (Ueda et al., 2013).

The availability of professional supports was important to mothers of children with intellectual disabilities but they also found informal supports to be helpful (McConkey et al., 2006). Among young children with developmental disability attending early childhood intervention programmes in Melbourne, support from extended family members accounted for a significant proportion of variance in predicting family quality of life (Davis & Gavidia-Payne, 2009).

Informal sources of support, especially other family members, play a crucial role in supporting families of children with disabilities. A substantial proportion of care for people with multiple disabilities in Australia was provided by family members and friends (AIHW, 2014). Support for families with disabilities in Japan often depends on

informal networks (Ueda et al., 2013) and it is highly likely that this is the scenario in Malaysia as well.

Mutual parent support groups help parents develop a sense of control of their situation, a sense of belonging to a community, and have been beneficial in instigating self-change (Solomon, Pistrang & Barker, 2001). Caregivers wanted to meet and talk with other parents of disabled children most (Suriati et al., 2011; Ueda et al., 2013). Caregivers feel emotionally supported and are able to obtain more resolutions from other parents who have children with similar health conditions (Suriati et al., 2011).

Level of family support may differ by child and family characteristics. Families of disabled children receive less material and emotional support than families without disabled children (Park et al., 2009). Mothers of children with cognitive delay received less informal support but more formal support than mothers of children without cognitive delay (Park et al., 2009).

In the US National Early Intervention Longitudinal Study (NEILS), families of ethnic minority reported lower levels of family and community support (Bailey et al., 2007). Families of children with poorer health also reported lower levels of support (Bailey et al., 2007).

## 2.8 Guiding framework for health service needs

Many conceptual frameworks or models related to improving community participation and quality of life of children with disabilities or special needs have been developed. These include early intervention models, quality of life frameworks for people with disabilities, models of family-centred services, models of coping and models of health promotion. Three conceptual models are outlined below.

The conceptual model of caregiving process and caregiver burden among the paediatric population (Appendix E) consists of six constructs; (1) background and context, (2) child characteristics, (3) caregiver strain, (4) intrapsychic factors, (5) coping/supportive factors and (6) health outcomes (Raina et al., 2004). The construct of background/context addresses the setting in which caregiving takes place, with emphasis on the socioeconomic characteristics of the family. The construct of child characteristics includes the characteristics of the child's impairment and the child's behaviour.

Caregiver demands and perception of formal care fall under the construct of caregiver strain. Self-perception under the intrapsychic factors construct is indicated by measures of caregiver's self-esteem and sense of mastery over the caregiving situation. Social support, family function and stress management are factors included in the coping/supporting factors construct. The health outcomes in the model are psychological and physical health.

The Life Needs Model of Paediatric Service Delivery (Appendix E) outlines the major types of service delivery needs of children and youth with disabilities, their families and their communities (King et al., 2002). Service programmes should be available throughout a child's life transition. Service delivery needs also encompass experiences in three spheres of life: personal (self-esteem and abilities), interpersonal (relationships)

and external (achieving roles in society such as having employment, education and living independently).

Services are grouped according to their focus on five types of needs: (1) need for foundational skills, (2) need for applied skills, (3) individual's need for support and information, (4) family's needs for support, information and skills, and (5) community members' needs for information and education. The long term outcomes of service delivery are community participation and quality of life.

Andersen's Behavioural Model of Health Services Use served as the guiding framework for this study. The model was developed in the late 1960s and has been adapted to different population groups and different types of services. In the model, Andersen puts forth the concept that people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care.

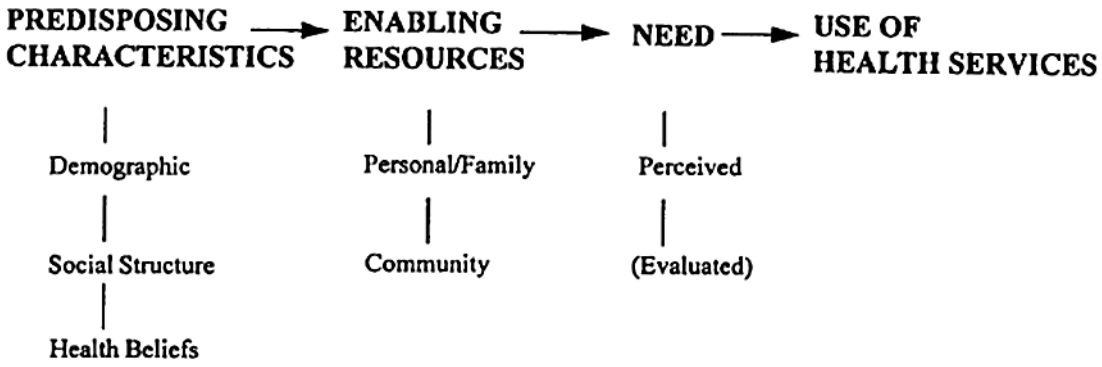


Figure 2.1: The Behavioural Model of Health Services Use (1960s), Andersen

Demographic factors, social structure and health beliefs are among the predisposing characteristics to use services. Demographic factors include age and gender. Social structure is traditionally measured by education, occupation and income but also includes the social networks and culture which determine a person's status in the

community. Health beliefs are attitudes, values and knowledge that people have about health and health services.

Enabling resources are found at the personal or community level, and the two are not mutually exclusive. Health personnel and facilities must be available and then, people must have the means and know-how to get to those services. Beyond looking at the availability of individual health care providers or types of services, the entire organization of medical care is an important enabling resource. How medical care is organized affects people's use of health services. Usage is also affected by the extent and quality of social relationships between the individual, his/her family and the community they live in.

A person's need for care can be looked at from his/her own perception (perceived need) or from the view of professionals (evaluated need). Perceived need can be explained as how people view their own health, how they experience illness, pain and worries about their health and whether or not they judge their problems to be of sufficient importance to seek medical help. It can be influenced by a person's social structure and health beliefs. On the other hand, evaluated need is professionals' judgement about a person's health status and whether the person needs medical care. Perceived need denotes a voluntary action on the part of the person seeking medical care whereas evaluated need would entail an effort on the professional's part to convince the person that he/she needs medical care.

Need for service is one of the most important predictors of use of services. Client expectations and preferences influence their willingness to engage in the process of therapy, thus it is imperative to understand client's needs and wants in relation to current and future services (Carroll, 2010). Parents who indicated a high level of need for respite care were considerably more likely to receive it (Douma et al., 2006). The

importance placed on services was a determining factor in whether Malaysian families made efforts to receive disability related services and actually received them (Clark et al., 2012).

Andersen (1995) defined equitable access as occurring when demographic and need factors account for most of the variation in health service utilization, while inequitable access occurs when social structure, health beliefs and enabling resources determine who gets medical care. To promote equitable access, the concept of mutability was introduced in the Behavioural Model. A variable is considered to have low mutability if it is not easily changeable or altered, and to have high mutability if it is.

Demographic and social structure has low mutability while health beliefs have medium mutability and enabling resources have high mutability. Demographic factors only explained 15% of the variation predicting total family needs (Farmer et al., 2004). It is more difficult to change a person's socioeconomic status or beliefs towards disability than to change the characteristics of community resources such as providing rehabilitation services closer to the community or training health staff to manage issues pertaining to disability.

Modifiable factors can be identified at both the agency and health system level. It is easier to evaluate and intervene in the service delivery process at the agency level, for example on the skills and attitude of staff at clinics or child centres. It is much more difficult to evaluate and intervene at the system level.

One of the ways to evaluate the health system as a whole would be to obtain information from studies done at different agencies and collectively analyse them. Although barriers are encountered at the individual family or agency level, they are generated and maintained by structural arrangements at the system level (Seid et al., 2004). Therefore, modifiable factors that are identified at the family or agency level can

inform changes at the system level and have the potential to affect not just individual families, but entire client populations.

There seems to be a social class gradient when it comes to health seeking behaviour. Studies on the utilization patterns of preventive, detection, diagnostic and treatment services have shown that services are used most by those who are relatively better educated and have higher income (Suchman, 1965). Service providers are usually concerned about whether people who have a disadvantaged social status get access to services that they need. Some children and families are more vulnerable to access problems in the health system due to socio-demographic factors such as minority status, living in poverty and lower parental education. However, enabling resources or service characteristics can actually ameliorate any effects of socio-demographic characteristics.

The Behavioural Model was used for this study because it can provide an understanding of why families use health services, as well as assist in defining and measuring equitable access to health care, through examination of the constructs of predisposing characteristics, enabling resources and needs. The Conceptual Model of Caregiving Process and Caregiver Burden addressed predisposing characteristics and enabling resources but it did not include the construct on needs, while the Life Needs Model of Paediatric Service Delivery focused only on the need construct.

Others have also used the Behavioural Model to guide research on factors affecting unmet service needs or family needs (Mayer et al., 2004; Almasri et al., 2011). Structural equation modelling revealed that the constructs of child characteristics, family characteristics and service characteristics explained between 32 - 43% of the variance of family needs (Almasri et al., 2011).

## 2.9 Objective and methods of studying health care services

Three major purposes for collecting disability data include: monitoring the level of functioning in a population, designing service provision, and assessing the equalization of opportunity (Mont, 2007). Disability data can be collected through population censuses, sample surveys and administrative registries (WHO/ESCAP, 2008). An overview of disability data which is available in Malaysia currently and the problems associated with them are presented in Appendix F.

National disability surveys are usually conducted via telephone interviews or via interviews by field workers in subjects' homes. These surveys are usually conducted after population censuses which serve to identify people with disabilities.

Other researchers have studied families of children with disabilities who are identified from registries (Perrin et al., 2000; Thyen et al., 2003; Warfield & Gulley, 2006; Kertoy et al., 2012). In addition, there have been studies on children with specific types of disability/ undergoing specific intervention programmes (Hendriks et al., 2000; Poon et al., 2014). The former usually utilizes mailed questionnaires, while the latter often employs research workers who interview subjects recruited from specialized clinics or intervention centres.

Health care service assessment may focus on the different aspects of care (Structure, Process and Outcome) expounded by Donabedien. *Structure* refers to attributes of the settings in which care occurs, *process* refers to what is actually done in giving and receiving care and *outcome* refers to the effects of care on the client. Satisfaction is a consequence of the whole experience of care – a reaction to structure, process and outcome (Donabedien, 1988).

Examination of these service elements is useful to inform service providers about areas of weaknesses. Measurement approaches can choose to focus on Structure (measuring actual receipt of services and structural quality), Process (measuring quality and processes of received care) and Outcome (measuring the outcomes of received care).

Structural elements include the availability of services, convenience of access to services, service cost, bureaucratic arrangements, waiting times, amount, frequency, length or quantity of service, appropriateness of services received and satisfaction with the physical facilities in which services are provided.

Process elements include receiving respectful and supportive care, professional competence, awareness of the needs of the child, enabling or partnership, continuity and coordination of care, amount of information and content of information provided.

Information on Outcomes can be used as evidence of whether a programme at local community, state or regional level is resulting in perceived benefits to children and their families. The adoption of the WHO International Classification of Functioning, Disability and Health has resulted in outcomes being measured in terms of activity participation, taking into account social and environmental factors, besides measuring outcomes in terms of impairments of body functioning. Most outcome measurements are being used to monitor children's progress in treatment and effectiveness of medical procedures. Some studies measure outcome of therapy or rehabilitation programmes.

Health related quality of life (HRQOL) is a popular outcome measure in health research. The Pediatric Quality of Life Inventory (PedsQL) and KIDSCREEN-52 are examples of instruments used to measure health-related quality of life in children (Huang et al.; Nezu et al., 2014). In tandem with the shift from child to family focused, QOL measures for the family have also been developed and tested (Varni, Sherman, Burwinkle, Dickinson & Dixon, 2004; Rahman et al., 2011; Samuel et al., 2012).

Lack of accessibility to services is associated with dissatisfaction, but lack of availability of services is not. One cannot be dissatisfied with something that is not available, but feeling deprived of something that exists can be a major source of dissatisfaction (King et al., 2001).

In a Malaysian study, families of disabled children viewed disability related services as important and were generally satisfied with services (Clark et al., 2012). However, they did not have much opportunity to receive services and they were not so likely to receive services that they need. Satisfaction with services was increased when families attained those services, or at least felt that they had opportunities to receive those services, could make efforts to attain those services or that the services could be improved.

All these point to the availability and accessibility of services as crucial elements that determine attainment and satisfaction with services. Outcome of service is a less important aspect of satisfaction with care compared to structure and process elements (King et al., 2001).

The European DISABKIDS group identified the following basic components to health needs assessment of children with chronic conditions: (i) health care needs, (ii) the receipt of services, (iii) the problems with receiving services and (iv) the appraisal and satisfaction with the quality of care (Schmidt et al., 2008). The first three components are the structural aspect of services and are measured by current utilization of health services, difficulty of accessing services, and unmet needs.

*Health care utilization* refers to the receipt of specific health care services. *Access to services* refers to the ease or difficulties of getting a certain service, which may depend on the extent to which the services is available. *Unmet needs* are used to assess equity of access to medical care across population subgroups.

Unmet need for health services is used to capture the degree to which needed health services are not received (Mayer et al., 2004; WHO, 2011) and is an indication of access problems or the difficulties experienced in the process of obtaining care.

Lack of access to existing services is one of the major factors associated with dissatisfaction with health care services. Total number of unmet needs is inversely correlated to general satisfaction (Schmidt et al., 2007). Services must first be viewed as important, which motivates efforts towards attainment, and attainment of a need determines satisfaction and subsequently, quality of life. However, most studies on satisfaction/ dissatisfaction with services focus on how services are delivered rather than whether services are available or accessible. Studies on needs and unmet needs therefore give information on the availability and accessibility of services in respect to local settings.

The measurement of health care needs based on factual receipt of services is confounded by the disability characteristics of the child and the availability and accessibility of services. Children with higher number of functional limitations and higher severity are the highest users of ancillary and enabling services (Benedict & Farel, 2003). Because the type and severity of disability varies from one child with disability to another, there are no standards for how much services should be used by these children.

If services are not available and accessible, they will not be used despite being needed. Service utilization is affected by the local context of how health services are delivered and paid for. Utilization rates tell us how much care is received but does not tell us how much the service is available and the ease of which the child/family can access care.

Rates of utilization can be a proxy of access to care, but should be studied together with perceived needs. It tells us the 'supply' aspect of services, but not the 'demand' aspect. The idea to study not just receipt of services, but also perceived needs is essential in finding out how much the service can be accessed by those who need them. Studying unmet needs gives a more accurate picture of access to care from an equity perspective, compared to solely looking at utilization rates.

Studies on family burden, resources and supports do not involve direct assessment of health services but provide valuable information on the care of children with disabilities. Knowledge of resources available to families is essential in the study of child and family outcomes. Traditionally, researchers have used family income, parent education and other measures of socio-economic status to assess family resources. Alternative measures include available time, capacity of the family to meet their basic needs and family members' perceptions of available resources (Van Horn, Bellis & Snyder, 2001).

## 2.10 Instruments to assess child and family service needs

Instruments used in the needs assessment of children with disabilities/special health care needs and their families found in the literature are presented in Appendix G.

### 2.10.1 Content domains and items

Examination of these instruments revealed that health care needs can be broadly categorized into needs of the child with disability and needs of the family having a child with disability. Child's needs focused on specific healthcare and therapy needs while family needs dealt with types of support for the family.

Healthcare and therapy needs are needs for services such as service of a specialist doctor, physiotherapist and occupational therapist, need for medication, mental health services, home nursing services, special equipment and modifications to the home.

Family needs could be summarized into support, information, finances, child care and professional services domains. Some of the needs expressed by families are help with child's care, help with household tasks, respite care, needing someone to talk to, parental counselling, self-help groups, help with explaining to others, information about activities for the child, information about current and future services, help with transport costs, school services and coordination of services.

### 2.10.2 Response options to measure needs and unmet needs

Need for services and receipt of services could be measured as a simple yes/no response. It could also be measured on a Likert or categorical scale.

In the US National Survey of CSHCN, the New Zealand HDS and the Family Partners Survey, the respondents were first asked whether the sample child needed a certain service. If they responded that the service was needed, they were then asked whether the child received the needed service.

When asking about a child's need for a certain service, a yes or no answer may not tell us how much the child needs the service. To address this issue, some studies have opted to use scales to measure service need. This also applies to the question on receipt of services as the child may receive the service some of the time but not all of the time.

## 2.11 Study Objectives

From the literature, it is seen that children with disabilities have many health care service needs. But the question is do they always receive the services that they need? This study aims to answer that question by first looking at what are the health care services needed, and then, whether those needs are being met. Unmet health care service needs show the gaps in service delivery. Besides the needs of the child, the needs of the child's family are also important. The literature shows that families need information, psychosocial support, financial help, respite care and help with care coordination.

In health care service delivery, equity in access is a major concern. Do those who are in need of more help have access to services? To look at equity, we have to identify who are the children who have more unmet health care service needs, and who are the families with more caregiver needs.

What are the socio-demographic characteristics of these children and families which predispose them to having more unmet needs and caregiver needs? Does being in a lower socioeconomic group, minority ethnic group, having a child with a more severe condition and helpfulness of sources of family support affect the receipt of services?

What are the access problems that families of children with disabilities face? Access to health care services is largely enabled by the characteristics of the services itself. Are unmet health care service needs mainly due to problems with skills and resources, logistics or parent-provider relationship?

Other interesting questions are whether child and family characteristics influenced the likelihood of the child receiving therapy, the likelihood of the family experiencing a financial or employment problem and the reporting of helpfulness of informal and formal family support sources.

This study aims to provide information to service providers on health care service needs and caregiver needs, which can translate to improvements in service delivery, practice and advocacy. In addition, recognition of the financial impact and social support systems available to families of children with disabilities can help guide the planning and provision of these support services.

### 2.11.1 General objective

To investigate the perceived health care service needs and caregiver needs of children with disabilities in Penang, Malaysia, and whether current services are meeting those needs.

### 2.11.2 Specific objectives

a) To describe the perceived health care service needs of children with disabilities (CWD) and the magnitude of their unmet health care service needs
b) To determine child and family characteristics predisposing to having more health care service needs and unmet needs of CWD
c) To determine the caregiver needs of CWD and the child and family characteristics predisposing to having more caregiver needs
d) To identify problems faced by caregivers in getting access to health care services
e) To describe the utilization of rehabilitation services by CWD, the financial impact of the child's condition on the family and the social supports available to caregivers of CWD

## 2.12 Conclusion of chapter two

The existing literature on health care service needs, unmet needs and family needs of children with disabilities has been reviewed. But very little is known about these topics in Malaysia. Reasons for unmet needs form the barriers to care, which are categorized into demographic and social structure factors, beliefs on disability and treatment, and service characteristics. Care burden faced by families of children with disabilities can be seen from the aspect of financial impact and family well-being. However, having social support reduces this care burden.

Effective methods for health care needs assessment is needed to know how to allocate scarce resources in the health system and at the same time to ensure quality and patient centred health care. Health care needs can be measured objectively by the rates of utilization and factual receipt of existing health services, or subjectively by the perception of health needs and subjective experience of caregivers.

The next chapter describes the methodology of this study, including the development of the study questionnaire, which was guided by the literature review in this chapter.

# CHAPTER 3: METHODOLOGY

## 3.1 Introduction

This chapter begins with a description of the framework underlying this study. The Behavioural Model of Health Services Use was modified to suit the study population of children with disabilities. Then, the study design, study area and study population are presented. Details of the study instrument are described next, followed by calculation of sample size, sampling procedure and how data was collected. The methodology of data analysis, including how missing data was addressed, as well as a description of the variables, operational definitions and statistical analyses applied in this study are presented at the end.

## 3.2 Framework of the study

The Behavioural Model of Health Services Use framework was modified to suit the study population of children with disabilities in order to drive the conduct of this study. This framework has three main dimensions: Predisposing Characteristics, Enabling Resources and Needs (figure 3.1).

For Predisposing Characteristics, the sub-dimensions of demographic and social structure factors were maintained. Under demographic factors were child characteristics such as age of the child, severity of disability and whether the child has a behavioural problem. Family characteristics including the education level and household income of the caregivers were grouped under social structure factors.

Health beliefs were changed to beliefs on disability. Beliefs on disability came from existing knowledge on disability and treatment, values placed on disability and attitudes towards services for children with disabilities. However, beliefs on disability were not in the scope of this study.

Instead of personal/individual or family factors, Enabling Resources was changed to encompass the availability and organization of services for children with disabilities, and the social supports available to access those services. Concepts of access problems and barriers to care are incorporated into this dimension. Among the commonly cited barriers in seeking and accessing care are logistic issues and the skills to navigate the health care system.

Needs were categorized into Child Needs and Caregiver Needs. Child Needs were needs for specific medical services and assistive devices, while Caregiver Needs were grouped into Need for Community Services, Information Needs, Financial Needs and Support Needs. In the original model, needs was categorized into perceived and evaluated needs. For the purpose of this study, only perceived needs were measured.

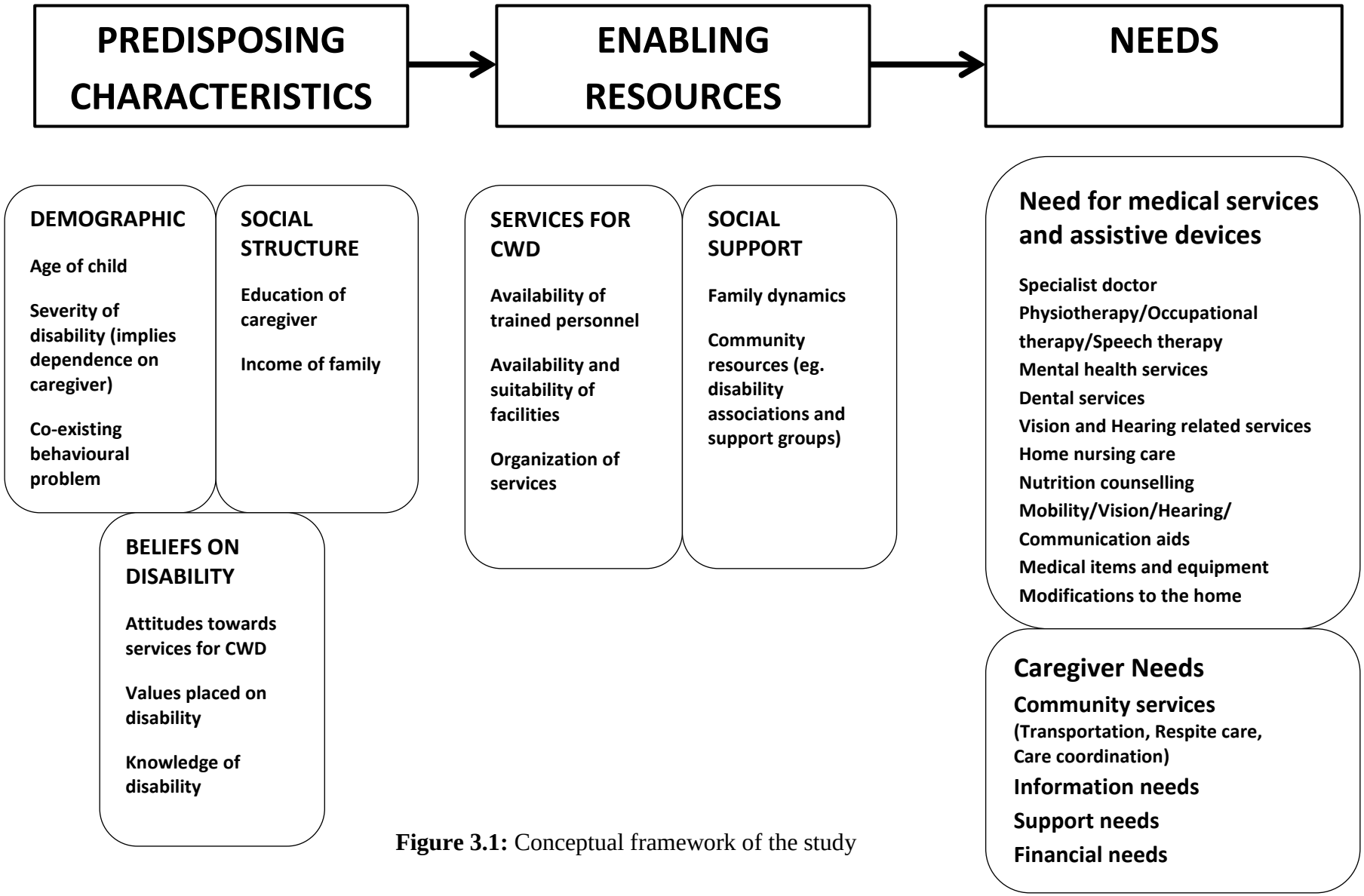


**Figure 3.1:** Conceptual framework of the study

### 3.3 Study design

This study serves as a preliminary audit of services for children with disabilities and their families in Malaysia. The study design is cross-sectional and data was collected through a mailed survey questionnaire sent to caregivers of children with disabilities identified from a national registry. A cross sectional study was chosen because data on individual characteristics, including predisposing factors and data on the outcomes of unmet health care service needs and caregiver needs could be collected. Since the purpose of this study is descriptive, this study design is considered adequate.

### 3.4 Ethics

Ethical approval was obtained from the University Malaya Medical Centre Ethics Committee and the research was also registered in the National Medical Research Register (refer Appendix B). For registration in the NMRR, ethical clearance was received from the Medical Research Ethics Committee. Permission was also obtained from the Penang Department of Social Welfare to access their registry.

### 3.5 Study area

The study area is the state of Penang in Northern Malaysia, a state with a land area of 1,031 $km^2$ and a population size of 1.64 million in 2013. The state is divided into two areas: the island and the mainland, which is also known as Province Wellesley (Seberang Perai). There are two districts on the island (North-east and South-west districts), and three districts on the mainland (North, Central and South Seberang Perai). All five districts in Penang were covered in the study (figure 3.2).

The prevalence of persons with disabilities in Penang as a percentage of the total population is 1.2% in year 2009, and this figure does not vary much between the different states in Malaysia, with the lowest percentage in Sabah (0.5%) and the highest in Perlis (2.0%) (DSW, 2009b). From a list of 61 organizations related to children with disabilities (NECIC, 2012), 11 are located in Penang, 8 in Perak, 10 in Sarawak, 5 in Malacca, 2 in Sabah, 1 in Terengganu, 17 in Selangor and 7 in the Federal Territory of Kuala Lumpur. From this distribution, we can see that most organizations are concentrated in Selangor, while some states have none. The study is suitable to be conducted in Penang because it has a high number of organizations providing services for children with disabilities relative to its population.


**Figure 3.2:** Map of Penang (Pulau Pinang) state in Peninsular Malaysia and the districts in Penang

### 3.6 Study population

The study population is the caregivers of children with disabilities aged 12 years and below who are registered with the Penang Department of Social Welfare in 2012. The number of registered children with disabilities given by the Department of Social

Welfare in table 3.1 below has to be viewed with caution because the statistics are cumulative and do not take into account the movement from one age category to another as the child grows up. Figures for new cases are added to the figures for existing cases every month.

In addition, Malaysia used a different categorization for disability prior to 2010. The old categories for disability were vision, hearing, physical, learning, cerebral palsy and others. The new categorization does not have cerebral palsy and others, but has speech, mental and multiple disabilities categories. It is not clear how the figures using the old categorization were incorporated into the new categorization. For example, figures for cerebral palsy in the old categorization can be put into physical or multiple in the new categorization.

**Table 3.1:** No. of registered cases in Penang by age group and type of disability, June 2012

| Type of disability | <6 years | 7 – 12 years | Total |
|---|---|---|---|
| Vision | 110 | 192 | 302 |
| Hearing | 191 | 323 | 514 |
| Physical | 576 | 709 | 1285 |
| Learning problems | 982 | 1787 | 2769 |
| Speech | 2 | 6 | 8 |
| Mental | 2 | 10 | 12 |
| Multiple | 144 | 89 | 233 |
| Total | 2007 | 3116 | 5123 |

Source: Penang Department of Social Welfare

### 3.6.1 Inclusion criteria

The inclusion criteria for the population in this study are:

a) Children identified to have any of the types of disability as defined in Malaysia's Persons with Disabilities Act 2008
b) Children aged 12 years and below
c) Children being cared for in a family setting

Children, and their families, have different needs at various ages (King et al., 2002). After the age of 12, the degree of independence the child achieves and adolescent issues need to be considered. This study chose to focus on children aged 12 years and below. By this age, most caregivers would either have figured out or given up on how to navigate the different systems involved in their child's care. Ministry of Health collated data from hospitals and health clinics show that 92 – 94% of newly detected and registered special needs children were aged 0 – 12 years (UNICEF, 2014).

Only children who were being cared for at home and not in an institutionalized environment were selected for the study because caregivers in these two settings may differ in their perceived needs. The questionnaire was designed for caregivers in a family home and not for caregivers in a residential home.

### 3.6.2 Exclusion criteria

a) Families for which no means of contact was available (those without either telephone number or home address)
b) Children staying in residential welfare homes
c) If there were two or more children with a disability in the family, only one child in the family was randomly chosen, to avoid the caregiver from participating in the study multiple times
d) Children who have passed away
e) Families which have moved to another state

## 3.7 Study instrument

A self-administered questionnaire with the following sections was developed for the purpose of this study:

a) Socio-demographic information
b) Financial impact
c) Education support needs
d) Utilization of rehabilitation services
e) Child's needs for services/assistive devices
f) Barriers to care - Reasons for not receiving services or assistive devices that were needed
g) Caregiver Needs Scale
h) Family support, incorporating Family Support Scale - measures the helpfulness of sources of support that parents receive
i) ABILITIES Index – describes the functional abilities and limitations of children across nine domains

The section on Child's needs for services/assistive devices answers the objective of describing the perceived health care service needs and unmet needs of children with disabilities, while the section on Caregiver Needs Scale answers the objective of determining caregiver needs. Socio-demographic information is gathered to determine the child and family characteristics associated with the health care service needs, unmet needs and caregiver needs. The ABILITIES Index is used to measure the severity of disability as one of the child characteristics which can influence needs and unmet needs. To answer the objective of identifying problems faced by caregivers in getting access to services that they need, the section on Barriers to care is referred to. The last objective on describing the utilization of rehabilitation services by CWD, the financial impact of the child's condition on the family and the social supports available to caregivers are covered in the sections on Financial impact, Utilization of rehabilitation services and Family support, respectively.

### 3.7.1 Development of questionnaire

A multi-stage process was involved in developing the study questionnaire: (i) literature review to identify content domains, (ii) getting input from experts, and (iii) obtaining feedback from service users through a pre-test.

The study questionnaire contains sections on assessment of child needs and assessment of caregiver needs. To develop the questions for these sections, first a literature review was conducted.

#### 3.7.1.1 Literature review for development of questionnaire

A literature review was carried out to find operational measurements or instruments assessing the needs of children with disabilities and/or their families or caregivers. The objective of identifying and examining these instruments was to determine item content and response options for use in the study questionnaire. Because there was a paradigm shift in the way disability services were provided in the 1990s from child focused to family focused, we decided to search only articles post 1990. Also, because the needs of families caring for a child with disability are fairly universal and are independent of the child's diagnosis, we did not search for studies which were disease or condition specific.

Articles were searched from Medline and Cinahl for articles from 1990 to 2012, using the following search terms: "Children with Disabilities", "Children with Special Needs", "Unmet Needs" and "Needs Assessment". We took into account study populations of children with disabilities (regardless of the type of disability), children with special health care needs, and children with chronic health conditions to include more instruments.

After screening through titles and abstracts, the full text of relevant articles were retrieved. Articles were also searched by manually searching references from original articles. Methodological reports of country disability surveys were also searched and retrieved if they were available online. Only articles in the English language, studies which involved assessment of child, family or caregiver needs, and studies which described how they operationalized the measurement of these needs adequately were included for examination.

Appendix G shows the content domains and response scales for the instruments used to assess child and family needs.

#### 3.7.1.2 Input from experts

Once a draft of the questionnaire was prepared, experts on the subject matter were approached to review the item content of the questionnaire. These experts comprised of 2 community paediatricians, 2 general paediatricians with special interest in children with special needs, 2 Ministry of Health staff in the PWD Health Unit and 2 NGO staff working with special needs children. Feedback from the experts was taken into consideration when revising the questionnaire.

#### 3.7.1.3 Feedback from service users

A pre-test of the questionnaire was carried out in the outpatient paediatric clinic in Hospital Seberang Jaya, a specialist hospital in the state of Penang, in January 2013. Twenty-two parents of children with disabilities (13 with learning disabilities, 8 with multiple disabilities and 1 with hearing disability) who attended the paediatric clinic completed the self-administered questionnaire and provided feedback on their understanding of the items.

Based on the feedback from the pre-test, certain questions were rephrased to better reflect item intent. For example, “help paying for educational services” under financial needs was rephrased to “help paying for educational and therapy services” because parents often associated “education” with formal schooling only, whereas some forms of therapy are also for educational purposes.

### 3.7.2 Sections in the questionnaire

a) Socio-demographic information

Demographic and social structure factors which make up the Predisposing characteristics in the framework of the study consist of child and family characteristics.

Questions were asked about child characteristics including age, ethnicity, type of disability and whether the child was bedridden. "Bedridden" here means totally dependent on others for mobility and had to be carried around. Caregivers were asked to give a general rating score for their child's severity of disability on a scale of 1 to 5 (1 being least severe and 5 being most severe), by thinking of how much or how often their child's disability affected his/her ability to do things other children his/her age do. They were also asked to indicate from a list how their child's disability occurred, based on what they had been told or from what they knew.

Questions on family characteristics included caregiver's age, highest education level, marital status, total number of children, number of children with disabilities and whether the caregiver had any medical illness. Information on average monthly household income and the sources of income such as from work/salary, from the Department of Social Welfare, or from other sources such as other family members or welfare organizations, were also obtained.

b) Financial impact

Information on out-of-pocket care expenditure of the disabled child in the past one year was requested. Respondents were asked how much they had to spend on doctor's visits, hospitalization, prescribed medicine, complementary medicine, medical supplies or equipment, dental services, other allied health services, transportation to medical

appointments, payment for child care, alternative treatment, education and other care related expenses.

Respondents were asked to what extent expenses for the child's care has caused financial problems and employment problems. The employment problems included having to stop work, taking too many leave days and whether the caregiver or his/her spouse had problems taking time off work to attend to the child's needs.

c) Education support needs

Respondents were also asked whether they had heard of early intervention (for those with children aged 0 – 3 years) and whether they had problems finding a suitable pre-school or school for their child (for older children).

d) Utilization of therapy/rehabilitation services

Respondents were asked the frequency of their child receiving therapy or rehabilitation services from government hospital, government health clinic, community based rehabilitation centre, private centres and non-governmental organizations. They were also asked the frequency of home visits by a health clinic nurse or PDK worker, if applicable.

e) Child's need for services/assistive devices

Respondents were asked whether their child needed 10 types of services and 7 types of assistive devices. Services included those of a specialist doctor, physiotherapy, occupational therapy, speech therapy, psychological services, dental services, vision related services (such as optometry), hearing related services (such as audiometry),

home nursing care, dietary or nutritional advice. Assistive devices included mobility aids, vision aids, hearing aids, communication aids, disposable medical items, special medical equipment and home modifications (such as hand rails and wheelchair ramps).

They were then asked whether their child received those services/assistive devices (i) fully/all the time, (ii) partly/sometimes or (iii) not at all.

f) Barriers to care

This section on Barriers to Care was mainly concerned with the service characteristics affecting access to care; i.e. the skills and resources, logistics and parent-provider relationship affecting access to care.

Respondents were asked to indicate why their children did not receive needed services/assistive devices by answering yes/no to a list of reasons given, which included statements on problems with availability of services/assistive devices, problems with costs, logistic problems or problems with service providers. In reference to the study framework, trained service providers and suitable facilities are Enabling Resources.

g) Caregiver Needs Scale (CNS)

Items in the Caregiver Needs Scale are presented in table 3.2 by their domains. The CNS had a total of 20 items. The items in each subscale were scored on a Likert scale: 1 = Help not at all needed, 2 = Help rarely needed, 3 = Help sometimes needed, 4 = Help very much needed, 5 = Help extremely needed. The minimum total score for the CNS is 20 and the maximum score is 100.

**Table 3.2:** Items in the Caregiver Needs Scale grouped by domains

| Help finding Community Services | Information Needs | Social Support Needs | Financial Support Needs |
|---|---|---|---|
| Finding transport to medical appointments<br><br>Finding trained person for day care<br><br>Finding respite care<br><br>Finding suitable education/therapy for child<br><br>Finding social or recreational activities for child<br><br>Getting care coordination | Information on child's disability<br><br>Information on current services available for child<br><br>Information on future services for child<br><br>Information on how to integrate therapy into daily activities<br><br>Information on how to handle child's behaviour<br><br>Information on how to play or communicate with child | Having someone to talk to about problems<br><br>Learning how to manage stress<br><br>Opportunities to talk to other parents of disabled children<br><br>Having more time for oneself | Help with paying for daily expenses<br><br>Help with paying for child's education/ therapy<br><br>Help with paying for special equipment/ toys that child needs<br><br>Help with paying for child care |

Exploratory factor analysis revealed four subscales used for analysis: need for 'Help getting information and services for the child' (5 items), 'Help coping with the child' (6 items), 'Help getting child care' (3 items) and 'Help with finances' (3 items). Three items with factor loading <0.4 were dropped from analysis. Cronbach's alpha coefficients of the subscales ranged from 0.813 to 0.903. Total CNS score correlated with number of child's needs ($r = 0.450$, $p < 0.001$) and unmet needs ($r = 0.312$, $p<0.001$). The score was also higher in families with financial and employment problems. Further elaboration on the development and psychometric properties of the CNS is provided in Appendix H.

h) Family support, incorporating modified Family Support Scale (Dunst, Jenkins & Trivette, 1984)

The well-being of a family which is exposed to a stressor is moderated by how they cope and this is influenced by what supports families have available to them. Social support is considered an Enabling Resource in the study framework.

Questions on family support included whether the caregiver has someone to help in the day to day care of the child (besides the spouse), who that person was and whether the caregiver joined any support group or organization related to the child's disability. Examples of organizations are Down Syndrome Association and National Autism Society of Malaysia (NASOM).

Helpfulness of sources of support was examined using a modified Family Support Scale (FSS). The scale consists of 18 items grouped into two subscales: informal support sources which consist of the caregiver's parents, spouse's parents, caregiver's relatives, spouse's relatives, spouse, caregiver's friends, spouse's friends, children, other parents, and co-workers, and formal support sources such as parent groups, social groups/clubs, church members/minister, family general practitioner, early childhood programmes, school/day care centre, professional helpers such as social workers, therapists and teachers, and professional agencies such as public health and social services.

The parent rates each source of support on a 5-point Likert scale, ranging from not at all helpful (1) to extremely helpful (5). A score of 0 is given if the source is not available to the family. Scores can range from 0 – 70.

Based on the feedback from the respondents during the pre-test, the Family Support Scale in this study was modified into 14 items. Caregiver's parents, spouse's parents, caregiver's relatives, spouse's relatives, spouse, children, co-workers and school/ day care centre were retained in the modified scale.

Exploratory factor analysis revealed four subscales, with all formal support sources loading into one construct and informal support sources loading into three constructs. The Cronbach's alpha for the modified 14 item FSS was 0.841, for informal FSS was 0.779 and for formal FSS was 0.762. FSS score did not correlate with any of the Caregiver Needs subscale scores ($r = -0.078$ to 0.070) or number of unmet needs ($r = -0.001$). FSS score could not differentiate between those having financial problem from those who did not, but it could differentiate between those having employment problem from those who did not. Although the modified FSS did not show good criterion validity, the results could also suggest that families who the need the most help are not getting enough support. Further elaboration on the psychometric properties of the modified FSS is provided in Appendix H.

"Caregiver's friends" and "spouse's friends" were grouped together under "friends". "Other parents" were specified as "parents of other children with special needs". "Church members/minister" was initially rephrased into "church/ mosque/ temple members" in view of Malaysia's multi-religion society. However, "Parent groups", "social groups" and "church/ mosque/ temple members" were dropped after the pre-test as respondents felt the people in this group were also "friends" or "parents of other children with special needs". Early childhood programmes are not commonly found in Malaysia, so this item was dropped as well. "Professional helpers" and "professional agencies" were expanded into the following items: health care workers, social welfare department, education department and non-governmental organizations.

i) ABILITIES Index (Simeonsson & Bailey, 1991)

Severity of disability is one of the child predisposing characteristics that influences needs. The ABILITIES Index is an instrument designed to describe, and provide a profile for, the functional abilities and limitations of children across nine domains. The nine domains are: Audition (hearing), Behaviour and social skills, Intellectual function, Limb functioning, Intentional communication, Tonicity, Integrity of physical health (general health), Eyes (vision) and Structural status. The authors of this instrument allow its use as long as the source is recognized. Its cross-cultural applicability to measure the functional level of children with disabilities in non-Western cultures has been documented (Simeonsson, Chen & Hu; Park et al., 2009; Poon et al., 2014).

A score was given to each item in each domain to rate the severity of the child's disability ranging from 1 (normal) to 6 (profound). Total scores range from 19 – 114. For the domains of Audition, Behaviour and social skills, Limb functioning, Intentional communication and Eyes (vision), a mean score was calculated for each domain and its degree of functioning categorized accordingly. For the domain of Tonicity, the highest score from either hypertonia or hypotonia was used to categorize the degree of functioning.

Instruments such as the Paediatric Symptom Checklist were considered for assessing disability, but these instruments acted as screeners for physical, cognitive, emotional or behavioural problems in children, and were not suitable for the study population which is children who were already diagnosed to have a disability. Other measures of function and disability such as the Children's Global Assessment Scale and Columbia Impairment Scale were also considered for rating of severity of disability.

In the end, the ABILITIES Index was deemed to be relatively easier to understand and less time consuming compared to the other measures. A simpler measure is desirable because the questionnaire is self-administered, encompasses caregivers of different educational backgrounds and is integrated into a questionnaire that already has many other sections. A questionnaire which is too long is a deterrent to quality completion.

## 3.8 Sampling

### 3.8.1 Sampling frame

The sampling frame was obtained from the Penang Department of Social Welfare's database of children with disabilities registered with them as of November 2012. There were 1392 children aged 12 years and below (born year 2001 onwards) in the database, after removing duplicate cases. This number is far below the statistic provided by the department earlier. Furthermore, this number may not be accurate because the database was started in 2011 and only new registrations or re-registrations were entered.

After excluding families for which no means of contact was available, children staying in welfare homes and children who had siblings who were also disabled (only one child was chosen to be in the sample from the same family), the number of children in the sampling frame was 1340 (figure 3.3).

This was the best sampling frame that could be obtained. The main deficiency of relying on administrative data, i.e. missing out on children who do not appear on administrative records because of recording oversights or lack of access to care, is recognized. Unless a complete database or census data is available, the actual number of children with disabilities at any one point in time is unknown. For this study, the sampling frame was stratified according to type of disability.

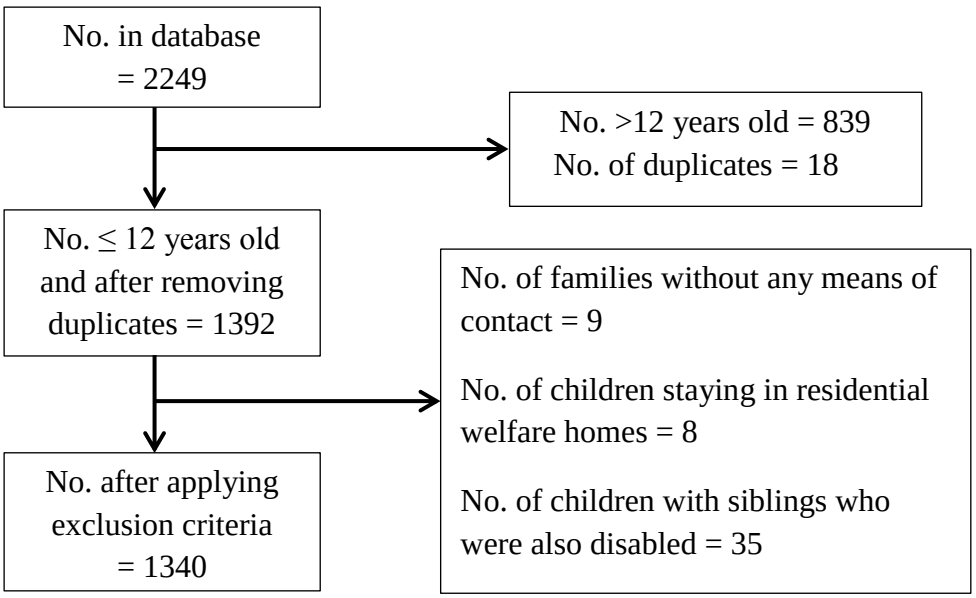


**Figure 3.3:** Flow chart of sampling process to arrive at sampling frame

### 3.8.2 Sampling method

Stratified sampling is chosen so that analysis of individual strata is permitted in addition to analysis of the total sample. Sampling according to type of disability also ensures that it is more representative of the population.

Stratified sampling can be done via proportionate or disproportionate allocation. Disproportionate stratified sampling was chosen because the subgroups of type of disability in the population of children with disabilities vary greatly in their sizes. The subgroups would also have different variances in the variables of interest. For example, children with physical disability would have different characteristics from children with learning disability.

Another reason disproportionate stratified sampling was chosen is to look at the similarities and differences among the subgroups. Thus, sufficient numbers must be selected from each subgroup of type of disability. In order to estimate population

parameters later on, the population composition were used as weights to compensate for the disproportionality in the sample.

A calculation of required sample size for this study has to take into account its stratified sampling design. The Effective Sample Size is the sample size that is required to obtain the same level of precision as in a simple random sample. It is calculated from the design effect, whereby the number of units within each stratum has to be known.

Unfortunately, information that is needed to calculate the design effect, and subsequently the required effective sample size could not be obtained from other studies. Other studies either looked at only one type of disability or the stratification in other studies was different from that used in this study. There was a lack of information on the number of people exposed or not exposed with a certain outcome by strata.

Nevertheless, sample size estimation for a similar population was still attempted to give an idea of the approximate number needed in the sample to prevent under-sampling.

### 3.9 Sample size

The results from the United States National Survey of Children with Special Health Care Needs were used to estimate the sample size because it took into account all children with special needs. Sample size was calculated using the Epi Info 7 programme.

Findings from van Dyck et al. (2004) showed a significant association between federal poverty level and unmet need for specific care services. Sample size for a cross-sectional study requires information on the ratio of people without a certain exposure to those who were exposed. It also requires information on the odds ratio between those exposed and unexposed who have the outcome of interest, and information on either the

percentage of those unexposed or percentage of those exposed with the outcome of interest.

For this calculation, the outcome of interest was any unmet need for specific care services (primary and specialty care services, ancillary services, supplies and equipment). The exposure was federal poverty level (FPL) <100% and no exposure was FPL>200%.[1] The ratio of unexposed to exposed was 5200/1255 = 4.2. With this information, the estimated sample size using Fleiss with continuity correction method was 223 (table 3.3).

**Table 3.3:** Sample size calculation for study population

Sample Size for Cross-Sectional Study

| | | | |
|---|---|---|---|
| Two-sided significance level(1-alpha): | | | 95 |
| Power(1-beta, % chance of detecting): | | | 80 |
| Ratio of sample size, Unexposed/Exposed: | | | 4.2 |
| Percent of Unexposed with Outcome: | | | 12 |
| Percent of Exposed with Outcome: | | | 32 |
| Odds Ratio: | | | 3.5 |
| Risk/Prevalence Ratio: | | | 2.7 |
| Risk/Prevalence difference: | | | 20 |
| | Kelsey | Fleiss | Fleiss with Continuity Correction |
| Sample Size - Exposed | 33 | 37 | 43 |
| Sample Size-Nonexposed | 137 | 154 | 180 |
| Total sample size: | 170 | 191 | 223 |

Sample size calculation for a population survey requires information on population size, expected frequency and design effect. The population size for this study was 1340. Expected frequency of unmet needs was left at 50% as it was unknown and the number

[1] Federal poverty level is calculated from the combination of household income and the number of persons in a household

of strata was 6 (for categories of visual, hearing, physical, speech, learning and multiple disabilities). An expected frequency of either <50% or >50% yields smaller sample sizes. A design effect of 1.0 as in simple random sampling with 95% confidence level produced a sample size of 300, whereas a design effect of 2.0 and 3.0 yielded sample sizes of 600 and 900 respectively.

.From the sampling frame of children with disabilities in Penang, children with learning disability make up 69.8% of the total and children with multiple disabilities make up 14.5%. For visual disability, the proportion was 3.5%, hearing disability 5.9%, speech 0.3% and physical 6.0%. The numbers in certain categories of disability were small. The number of children in the learning disability category was 936. Simple random sampling from only this category with expected frequency 50% and 95% confidence level yielded a sample size of 272.

Thus, a decision was made to randomly sample 400 out of 936 children in the category of learning disability, and all children in other disability categories (table 3.4). In the end, the sample size for this study was 804.

**Table 3.4:** Number of children with disabilities registered with the Penang Department of Social Welfare in 2012 and number of children sampled by disability category

| Type of disability | Number in population | Number sampled |
|---|---|---|
| Vision | 47 | 47 |
| Hearing | 79 | 79 |
| Physical | 80 | 80 |
| Learning | 936 | 400 |
| Speech | 4 | 4 |
| Multiple | 194 | 194 |
| Total | 1340 | 804 |

### 3.10 Data collection

The questionnaire was prepared in the Malay language, because it is the national language in Malaysia and that most of the population would be able to understand Malay. However, for certain phrases, a Chinese translation was added to enhance understanding among those of Chinese ethnicity.

A sampling frame of children with disabilities registered with the Penang Department of Social Welfare in 2012 was obtained with permission from the department. The questionnaire, patient information sheet and written consent form were mailed to 804 caregivers with a return-address envelope and stamp, since a face to face interview with all the identified caregivers was not feasible due to time and cost constraints faced by this researcher. Forms were also mailed to those whose telephone numbers were not available but whose mailing addresses could be obtained from the registry. The return of a questionnaire was taken to indicate the consent of the caregiver to take part in the study.

Confidentiality of the participants was assured by maintaining that any information provided would be used in aggregate form, and neither family nor the child would be identified individually in the presentation of results. Participants could also choose to return the questionnaire anonymously, without stating their name or their child's.

A list of places with services for children with disabilities in Penang and their contact details (including NGOs, hospitals and health clinics with rehabilitation services, PDKs and schools) was mailed together with the survey questionnaire. This action served as a responsibility on the part of the researcher to provide extra information on available services to the caregivers.

To ensure the best response rate possible, the researcher contacted the participants two to three weeks after mailing the questionnaire to confirm that they had received it and to remind them to send it back. Data was collected from Feb – June 2013. A total of 804 questionnaires were sent out. In the end, 305 questionnaires (37.9%) were returned (figure 3.4).

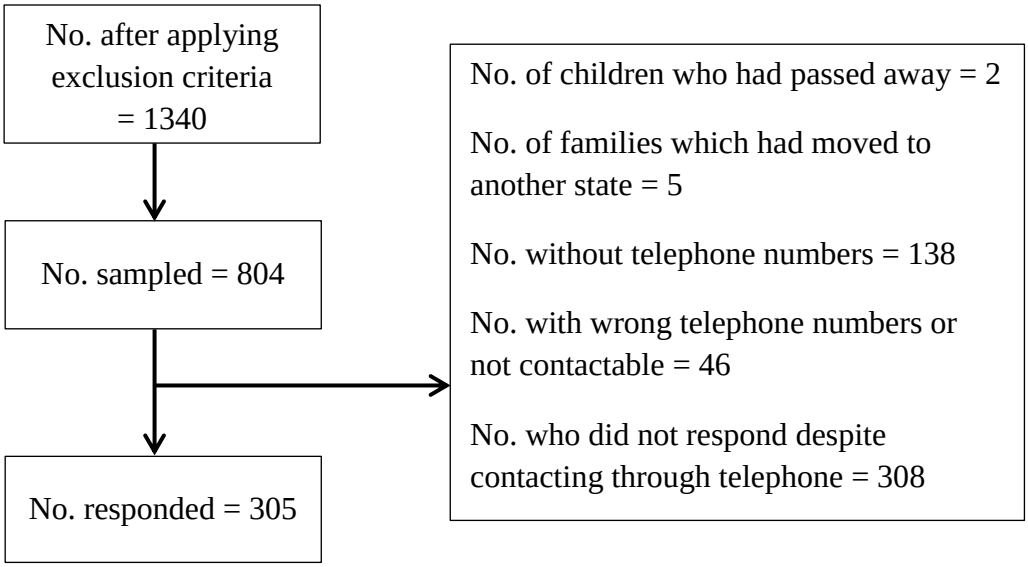


**Figure 3.4:** Flow chart of process to arrive at number of respondents

### 3.11 Data analysis

Data was analysed using Statistical Package for Social Sciences (SPSS) version 20.0. The data was cleaned before it was analysed.

#### 3.11.1 Weighting and addressing missing data

Results of this study can only be representative of the population of children with disabilities registered with the Department of Social Welfare in Penang. Data was weighted based on the respondent sample (table 3.5) in order to estimate population parameters. The population composition and non-response rate were used to calculate the weights in order to compensate for the disproportionality in the sample.

**Table 3.5:** Weights assigned to each stratum of type of disability

| Type of disability | Number in population | Number sampled | Number responded | Assigned weight |
|---|---|---|---|---|
| Vision | 47 | 47 | 17 | 2.76 |
| Hearing | 79 | 79 | 38 | 2.08 |
| Physical | 80 | 80 | 38 | 2.11 |
| Learning | 936 | 400 | 126 | 7.43 |
| Speech | 4 | 4 | 2 | 2.00 |
| Multiple | 194 | 194 | 84 | 2.31 |
| Total | 1340 | 804 | 305 | |

Missing data were excluded from analysis. Chi-square tests of significance were used to detect any differences in the baseline characteristics between respondents and non-respondents, as well as between completers and non-completers for the outcome variables. This was done in order to identify non-response or non-completion bias. Fisher's Exact test was used if the expected count in any cell in the 2 x k contingency table was $\leq 5$. For ordered categories, Chi-square tests for trend were used, while the Mann-Whitney U test was used to compare the ABILITIES Index scores.

### 3.11.2 Variables and operational definitions

a) Description of health care service needs

First, the percentage of caregivers reporting their child needing each service/assistive device (specialist doctor, physiotherapy, occupational therapy, speech therapy, psychological services, dental services, vision related services, hearing related services (such as audiometry, home nursing care, dietary or nutritional advice, mobility aids, vision aids, hearing aids, communication aids, disposable medical items, special medical equipment and home modifications) was calculated.

b) Description of unmet health care service needs

Out of those who answered their child needed a certain service/assistive device, the percentage that did not fully receive the service was calculated.

"Unmet need" in this study is defined as the child not fully receiving a service that was needed (receiving partially or did not receive at all). In the US National Survey of Children with Special Health Care Needs, "unmet need" was defined as the child not receiving *all* the services that was needed, and respondents could only answer Yes or No. There is no response option for a service being only partially received. The European DISABKIDS group in their CHC-SUN questionnaire defined a service as unmet only if the service was not received altogether. To give a more detailed picture in this study, analysis was conducted for both services not fully received (received partially or not received at all) and services not received altogether (only services not received at all).

Sub-analysis for different types of disability was also performed. Children with vision, hearing, speech and physical disability were grouped together under 'other disability'. Number of services needed and number of services unmet for each child was totalled and then averaged over number of children in the respective three categories of learning, multiple and other disability.

c) Association between child and family characteristics with health care service needs and unmet needs

Child and family characteristics asked in the socio-demographic section of the questionnaire were the explanatory variables. Child characteristics include age, ethnicity, disability category and severity of disability, while family characteristics

include parental education level, income level, number of children, number of disabled children in the family and whether either parent had a medical problem.

For the purpose of inferential analysis, highest education level of the primary caregiver was collapsed into three categories; 'none, primary or lower secondary', 'upper secondary' and 'tertiary'. Income level was categorized into 'bottom 40%', 'middle 40%' and 'upper 20%', following the format for population income composition reported in the Malaysian Household Income Survey 2012 by the Department of Statistics.

The outcome variables were:

a) Number of needs, defined as number of services and assistive devices needed (quantitative variable ranging from 0 – 17)

b) Number of unmet needs, defined as number of services and assistive devices needed but not fully received (quantitative variable ranging from 0 – 17)

Distribution of unmet needs was explored to find the number of categories that would be suitable for logistic regression. Converting the data into a dichotomous categorical variable (no unmet needs vs having unmet needs) rendered the group sizes to be grossly different, a non-desirable characteristic for logistic regression analysis.

Furthermore, there is another problem in the reporting of number of unmet needs, whereby the number of unmet needs cannot exceed the number of service needs reported. Children who only have two service needs cannot report having three or more unmet needs. But if they had both needs unmet, this can be considered a high level of unmet need, even though the actual number of services not fully received is only two.

In an attempt to overcome this problem, the ratio of number of services not fully received to the number of services needed was calculated. From this ratio, a latent ordinal variable "Level of unmet needs" was created with 3 categories: Low, Moderate and High unmet needs. If the ratio of number of services not fully received to number of services needed was 0 – 0.3, this was categorized as "Low unmet needs". A ratio of 0.31 – 0.70 was categorized as "Moderate unmet needs" and a ratio of 0.71 – 1.0 was categorized as "High unmet needs". Categorization of unmet needs in this manner enabled the number of respondents to be balanced across all three groups.

Another method of analysis was conducted whereby the sample was grouped into those who did not receive a needed service at all and those who received a service partially or fully, following the definition by the European DISABKIDS Group. The ratio of number of services not received at all to the number of services needed was calculated. A dichotomous categorical variable was created, which grouped the children into "Received needed services" (ratio = 0) and "Did not receive needed services" (ratio >0). The group sizes for the two categories were almost equal.

d) Determination of caregiver needs and its association with child and family characteristics

The percentage of caregivers who reported definitely needing help with each item in the Caregiver Needs Scale (CNS) was calculated. Respondents who gave a score of 4 (help very much needed) or 5 (help extremely needed) were categorized as definitely needing help with the item. The mean score for each item was also obtained by dividing the total score for that item with the number of respondents.

The mean score for each subscale in the CNS was used as the outcome variable for analysis of child and family characteristics associated with caregiver needs. The mean score was derived from dividing the total score for each subscale with the number of respondents and number of items in the subscale.

e) Description of access problems to health care services

Percentage of respondents who indicated each access problem was determined. This was done for the overall sample and also according to type of disability.

f) Description of utilization of rehabilitation services, the financial impact of the child's condition on the family and the social supports available to caregivers

The description of utilization of rehabilitation services included the percentage of children receiving therapy by disability category, frequency of therapy, number of facilities and type of facility. Financial impact was defined as the prevalence of family having financial and employment problem.

To study the factors associated with having financial problem among families of children with disabilities, the financial problem variable was dichotomized into two categories: big financial problem vs small or no financial problem. To study the factors associated with having employment problem among families of children with disabilities, employment problem was defined as caregiver having to stop work and/or taking too many leave days to attend to the child.

The distribution of the type and number of social supports available to caregivers was also obtained. From the modified Family Support Scale, the percentage of caregivers finding each source of support as helpful was determined. A score of 0 – 2 was

considered less helpful while a score of 3 – 5 was considered more helpful. Mean scores were calculated for each source of support, by dividing the total score for that item with the number of respondents. Higher mean scores indicated more helpfulness.

The mean score for each subscale in the FSS was used as the outcome variable for the inferential analysis on helpfulness of family support sources. The mean score was derived from dividing the total score for each subscale with the number of respondents and number of items in the subscale.

### 3.11.3 Statistical analysis

In view of stratified sampling, complex samples analysis method was performed to arrive at population estimates. Variance adjustment for complex sampling increases the standard errors in the data to reflect the added uncertainty associated with the method. This helps ensure that results from statistical analysis are not interpreted to be significant when they are not.

Depending on the distributions of the outcome variables of interest, different regression models were used. Complex samples general linear model regression was used when the outcome variable approximated a normal distribution. If the outcome variable was categorical, complex samples logistic or ordinal regression was applied.

The distributions for number of needs and Caregiver Needs Scale scores were found to approximate normal distributions. So, a complex samples general linear model was applied for the regression of these variables.

Number of unmet needs had a skewed distribution so it could not be analyzed using general linear model. There is a preponderance of zeros in this variable, meaning that many children did not have any unmet service needs. Sometimes, outcome variables are

log-transformed to get a normal distribution. However, this approach is not suitable for analysis of the 'unmet needs' variable because the zero count here is significant. Taking the log of zero would generate an undefined value and this will cause quite substantial loss of data.

Number of unmet needs were categorized into Low, Moderate and High unmet needs. This new ordinal variable, "Level of unmet needs", was analysed by complex samples ordinal regression using logit function. The cumulative response probabilities were from the lowest value to the highest value (from low unmet needs to high unmet needs). The exponential parameter estimates for independent categorical variables are the odds ratios (ORs) in relation to the reference categories. For continuous variables, the exponential parameter estimates are similarly interpreted as the odds of being in a higher unmet need category.

For the categorical outcome of financial/employment problem, complex samples logistic regression was performed. For regression of family support scores, a complex samples general linear model was used.

Both bivariate and multivariate analyses were performed. In bivariate analysis, the independent variables are entered into the respective regression models individually. Then, in multivariate analysis, the relevant independent variables are entered into the regression models. Multivariate analysis adjusts for confounders and reveals which variables are significant factors associated with the outcomes. The statistical criterion for inclusion of independent variables into multivariate analysis was variables which had a p value of $\leq 0.2$ on bivariate analysis (Maldonado & Greenland, 1993).

The number of independent variables to be entered into the multiple regression models is also limited by the sample size that had complete responses to all the independent and dependent variables. Based on the work of Peduzzi, Concato, Kemper, Holford and

Feinstein (1996), the following guideline for the minimum number of cases is suggested: N = 10 k / p (where p is the smallest of the proportions of negative or positive cases in the population and k is the number of independent variables). For all multiple regression models in this study, the minimum sample size was met.

Effect sizes in terms of $R^2$ values for quantitative variables and pseudo $R^2$ values for categorical variables are also reported. Results of effect sizes focus on the amount of variance accounted for by a certain predictor.

### 3.12 Conclusion of chapter three

In summary, a cross-sectional study was conducted among caregivers of children with disabilities aged 0 – 12 years registered with the Penang Department of Social Welfare in 2012. Stratified sampling was applied by type of disability. Data was collected through a mailed questionnaire answered by caregivers. The questionnaire included an assessment of the child's unmet need for 17 specific medical services and assistive devices, and a newly developed 20-item Caregiver Needs Scale (CNS). Data was analysed using complex samples regression models.

# CHAPTER 4: RESULTS

## 4.1 Introduction

This chapter begins with a description of the baseline characteristics of the study sample. A comparison between respondents and non-respondents, as well as between completers and non-completers for relevant outcome variables, are first presented to identify non-response and non-completer bias.

Secondly, the main results of this study are presented. These are the results on the prevalence of health care service needs and unmet needs for children with disabilities, followed by the child and family characteristics predisposing to these needs and unmet needs. The distributions of needs and unmet needs for specific services are detailed out for the overall study population and also for different categories of disability. The next section contains results on caregiver needs in reference to the Caregiver Needs Scale and its subscales, as well as the child and family factors associated with each subscale.

Thirdly, the utilization of rehabilitation services by different groups of children with disabilities is described. This is followed by the results of the financial impact experienced by families of children with disabilities. Results on income, care expenditure and factors associated with families having financial or employment problem are presented. The last section is on the supports available to these families, which includes results on informal and formal family support scores, as well as the factors associated with the helpfulness of these supports.

## 4.2 Baseline characteristics of the study sample

The baseline characteristics of the study sample for respondents and non-respondents are shown in table 4.1.

### 4.2.1 Distribution of respondents and non-respondents

Age of the child was categorized into three groups. A majority of the respondents had children aged 7 – 12 years (67.5%), 21.3 % had children aged 4 – 6 years and 10.8% had children aged 0 – 3 years. The children comprised of 192 (63.0%) boys and 112 (36.7%) girls. One respondent chose to remain anonymous on the child's age and gender.

By ethnicity, 63.3% of the children were Malay, 28.2% Chinese and 8.5% Indian. According to the Department of Statistics, the population composition in Penang in year 2013 was 40.9% Malay, 41.5% Chinese, 9.9% Indian, 0.7% other ethnicities and 7.0% other nationalities.

There were 48 (15.7%) children who were bedridden. These 48 children comprised of 43 children (51.2% out of 84 children) with multiple disabilities and 5 children (13.2% out of 38 children) with physical disabilities.

Using a simple scale for parental rating of child's severity of disability, 25.9% were rated as less severe, 43.0% moderately severe and 27.2% most severe. Out of all the respondents, 42.6% reported that the cause of the disability was congenital/ genetic, 17.7% due to complications at birth, 8.5% due to illness, 3.6% due to accident and 1.3% due to other reasons. However, 23.9% of respondents actually did not know the cause of the disability.

Only 2.0% of the primary caregivers were not the parents of the child. This included grandparents and other extended family members. Most of the caregivers (91.8%) were married and had secondary education (69.5%), 1.3% did not have any education, 7.2% had primary education and 21.6% had college or university education. The same trend was seen whether for fathers or mothers, with higher percentage completing upper

secondary education, followed by lower secondary, then college/university, primary education and lastly no education.

Caregivers reported that 28.5% of them had an existing medical problem. The percentage of families with five or more children was 16%. There was more than one disabled child in 12.1% of the families.

About 57.0% of the respondents in this study reported they were earning <RM2000/month, 27.5% reported they earned between RM2000 and RM3999, and 12.1% earned ≥RM4000/month. Distribution of households by income in the Malaysian Household Income Survey 2012[1] revealed that 22.8% of households earned <RM2000, 32.7% earned between RM2000 and RM3999, while 44.7% earned ≥RM4000. Taken together, this means that more children with disabilities come from families of lower income.

In this study, 43.0% of respondents reported spending <RM2500/year on care expenditure for their child with disability, 21.0% spent between RM2500 and RM4999, and 27.2% spent >RM5000/year. On analysis, both income and expenditure distributions were skewed, with more families in the lower income group and lower expenditure group.

[1]The Household Income Survey (HIS) carried out by the Department of Statistics reports the mean monthly gross household income in Malaysia as RM5000 in 2012. In Penang, the reported mean monthly income was RM5005. In 2012, the mean monthly gross household income in Penang for the bottom 40% was RM1847, for the middle 40% was RM4573 and for the top 20% was RM12,159.

**Table 4.1:** Baseline characteristics of children with disabilities registered with the Penang Department of Social Welfare (study sample and population)

| | Sample/ Respondents (n = 305) | | Non-respondents (n = 1035) | | p value | Total/ Population (n= 1340) | |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | | No. | % |
| **Age category** | | | | | 0.235 | | |
| 0 – 3 years | 33 | 10.8 | 152 | 14.7 | | 185 | 13.8 |
| 4 – 6 years | 65 | 21.3 | 212 | 20.5 | | 277 | 20.7 |
| 7 – 12 years | 206 | 67.5 | 671 | 64.8 | | 878 | 65.5 |
| Not answered | 1 | 0.3 | | | | | |
| **Gender** | | | | | 0.681 | | |
| Male | 192 | 63.0 | 667 | 64.4 | | 859 | 64.1 |
| Female | 112 | 36.7 | 368 | 35.6 | | 481 | 35.9 |
| Not answered | 1 | 0.3 | | | | | |
| **Ethnicity** | | | | | 0.050 | | |
| Malay | 193 | 63.3 | 580 | 56.0 | | 773 | 57.7 |
| Chinese | 86 | 28.2 | 366 | 35.4 | | 452 | 33.7 |
| Indian | 26 | 8.5 | 82 | 7.9 | | 108 | 8.1 |
| Others | 0 | 0 | 7 | 0.7 | | 7 | 0.5 |
| **Type of disability** | | | | | **<0.001** | | |
| Vision | 17 | 5.6 | 30 | 2.9 | | 47 | 3.5 |
| Hearing | 38 | 12.5 | 41 | 4.0 | | 79 | 5.9 |
| Physical | 38 | 12.5 | 42 | 4.1 | | 80 | 6.0 |
| Learning | 126 | 41.3 | 810 | 78.3 | | 936 | 69.9 |
| Speech | 2 | 0.7 | 2 | 0.2 | | 4 | 0.3 |
| Multiple | 84 | 27.5 | 110 | 10.6 | | 194 | 14.5 |
| **Primary caregiver** | | | | | | | |
| Parents | 298 | 97.7 | - | - | | - | - |
| Others | 6 | 2.0 | - | - | | - | - |
| Not answered | 1 | 0.3 | - | - | | - | - |
| **Marital status of primary caregiver** | | | | | | | |
| Single | 1 | 0.3 | - | - | | - | - |
| Married | 280 | 91.8 | - | - | | - | - |
| Widowed | 7 | 2.3 | - | - | | - | - |
| Separated/divorced | 9 | 3.0 | - | - | | - | - |
| Not relevant (not parents) | 6 | 2.0 | - | - | | - | - |
| Not answered | 2 | 0.7 | - | - | | - | - |

Table 4.1, continued

| | Sample/ Respondents (n = 305) | | Non-respondents (n = 1035) | | p value | Total/ Population (n= 1340) | |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | No. |
| **Father's highest education** | | | | | | | |
| No education | 5 | 1.6 | - | - | | - | - |
| Primary | 34 | 11.1 | - | - | | - | - |
| Lower secondary | 79 | 25.9 | - | - | | - | - |
| Upper secondary | 112 | 36.7 | - | - | | - | - |
| College/University | 54 | 17.7 | - | - | | - | - |
| Not relevant (mother single/ widowed or divorced) | 18 | 5.9 | - | - | | - | - |
| Not answered | 3 | 1.0 | - | - | | - | - |
| **Mother's highest education** | | | | | | | |
| No education | 6 | 2.0 | - | - | | - | - |
| Primary | 37 | 12.1 | - | - | | - | - |
| Lower secondary | 73 | 23.9 | - | - | | - | - |
| Upper secondary | 132 | 43.3 | - | - | | - | - |
| College/University | 46 | 15.1 | - | - | | - | - |
| Not relevant (father single/ widowed or divorced) | 8 | 2.6 | - | - | | - | - |
| Not answered | 3 | 1.0 | - | - | | - | - |
| **Primary caregiver's highest education** | | | | | | | |
| No education | 4 | 1.3 | - | - | | - | - |
| Primary | 22 | 7.2 | - | - | | - | - |
| Lower secondary | 65 | 21.3 | - | - | | - | - |
| Upper secondary | 147 | 48.2 | - | - | | - | - |
| College/University | 66 | 21.6 | - | - | | - | - |
| Not answered | 1 | 0.3 | - | - | | - | - |
| **No. of children** | | | | | | | |
| 1 – 2 | 126 | 41.3 | - | - | | - | - |
| 3 – 4 | 121 | 39.7 | - | - | | - | - |
| ≥5 | 49 | 16.0 | - | - | | - | - |
| Not answered | 9 | 3.0 | - | - | | - | - |

Table 4.1, continued

| | Sample/ Respondents (n = 305) | | Non-respondents (n = 1035) | | p value | Total/ Population (n= 1340) | |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | No. |
| **No. of disabled children in the family** | | | | | | | |
| Two or more | 37 | 12.1 | - | - | | - | - |
| One | 259 | 84.9 | - | - | | - | - |
| Not answered | 9 | 3.0 | - | - | | - | - |
| **Either caregiver has medical problem** | | | | | | | |
| Yes | 87 | 28.5 | - | - | | - | - |
| No | 213 | 69.8 | - | - | | - | - |
| Not answered | 5 | 1.6 | - | - | | - | - |
| **Child bedridden** | | | | | | | |
| Yes | 48 | 15.7 | - | - | | - | - |
| No | 257 | 84.3 | - | - | | - | - |
| **Parental rating on severity of child's disability**[#] | | | | | | | |
| 1 – 2 | 79 | 25.9 | - | - | | - | - |
| 3 | 131 | 43.0 | - | - | | - | - |
| 4 – 5 | 83 | 27.2 | - | - | | - | - |
| Not answered | 12 | 3.9 | - | - | | - | - |
| **Reason for disability** | | | | | | | |
| Congenital/genetic | 130 | 42.6 | - | - | | - | - |
| Complications at birth | 54 | 17.7 | - | - | | - | - |
| Due to illness | 26 | 8.5 | - | - | | - | - |
| Due to accident | 11 | 3.6 | - | - | | - | - |
| Others | 4 | 1.3 | - | - | | - | - |
| Don't know | 73 | 23.9 | - | - | | - | - |
| Not answered | 7 | 2.3 | - | - | | - | - |
| **Income category of household** | | | | | | | |
| <RM2000/month | 174 | 57.0 | - | - | | - | - |
| RM2000 – 3999/month | 84 | 27.5 | - | - | | - | - |
| ≥RM4000/month | 37 | 12.1 | - | - | | - | - |
| Not answered | 10 | 3.3 | - | - | | - | - |

Table 4.1, continued

| | Sample/ Respondents (n = 305) | | Non-respondents (n = 1035) | | p value | Total/ Population (n= 1340) | |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | No. |
| **Care expenditure category of household** | | | | | | | |
| <RM2500/year | 131 | 43.0 | - | - | | - | - |
| RM2500 – 4999/year | 64 | 21.0 | - | - | | - | - |
| ≥RM5000/year | 83 | 27.2 | - | - | | - | - |
| Not answered | 27 | 8.9 | - | - | | - | - |

[#] How much or how often the child's disability affected his/her ability to do things other children his/her age do, with 1 being least severe and 5 being most severe

Children with disabilities registered with the Department of Social Welfare were comparable in terms of age (p = 0.235) and gender (p = 0.681) composition between respondents and non-respondents. However, Chinese and children classified under "other ethnicity" were slightly underrepresented (p = 0.05). Information on other socio-demographic variables, in particular, caregiver's education and income level were not available from the registry.

According to type of disability, 41.3% of respondents had learning disability compared to 78.3% of non-respondents. This underrepresentation is corrected by weighting the study sample according to type of disability.

The mean age of the children in this study was 7.8 years and the mean number of children in the family was 3. The ABILITIES Index score, which rates the severity of the child's disability in nine domains, had a skewed distribution (skewness 1.06) with more children having lower scores. The mean score was 41.9 ± 17.1 and the median score was 36.0.

Children whose caregivers rated them as having moderate to profound degree of disability in a particular domain were considered as having a definite problem in that domain. Among the children, there were 13.8% with a hearing problem, 15.1% with a vision problem, 17.0% had a problem with limb functioning, 20.7% had abnormal muscle tone and 37.1% had a problem with intellectual functioning (table 4.2). The high percentage of children with physical, hearing or visual problems is because children with these disabilities were overrepresented in the sample relative to the population. This disproportion is corrected by weighting during inferential analysis.

**Table 4.2:** Representation of children by domains and degree of disability

| Domain of disability | Degree of disability (% of children, n = 305) | | | | | |
|---|---|---|---|---|---|---|
| | Normal | Suspected | Mild | Moderate | Severe | Profound |
| Hearing | 61.6 | 4.6 | 3.9 | 4.6 | 4.3 | 4.9 |
| Behaviour and social skills | 26.9 | 11.1 | 13.4 | 17.7 | 11.5 | 3.9 |
| Intellectual functioning | 26.6 | 9.2 | 9.8 | 21.0 | 10.2 | 5.9 |
| Limb functioning | 48.5 | 11.8 | 6.2 | 8.5 | 4.9 | 3.6 |
| Intentional communication | 22.3 | 8.5 | 13.1 | 21.0 | 12.1 | 6.6 |
| Tonicity | 48.2 | 5.9 | 8.5 | 12.5 | 4.9 | 3.3 |
| General health | 47.2 | 5.6 | 12.1 | 12.1 | 3.0 | 3.3 |
| Vision | 56.4 | 7.5 | 4.6 | 8.5 | 3.6 | 3.0 |
| Body structure | 52.5 | 6.9 | 7.9 | 8.5 | 5.6 | 1.6 |

It was found that 101 (33.1%) children in this sample had behaviour and social skills problem. Among those categorized to have this problem, 51 (50.5%) had learning disability, 42 (40.6%) had multiple disabilities, and 9 (8.9%) had other disability.

In addition, 121 (39.7%) children in this sample had problems communicating. Among those categorized to have this problem, 60 (49.6%) had learning disability, 46 (38.0%) had multiple disabilities, 13 (10.7%) had hearing disability and 2 (1.7%) had other disability.

### 4.2.2 Distribution of completers and non-completers

The number and percentage of completers and non-completers for the relevant outcome variables are shown in table 4.3.

**Table 4.3:** Distribution of completers and non-completers in study sample for relevant outcome variables (n = 305)

| | Completers | | Non-completers | |
|---|---|---|---|---|
| | No. | Percentage | No. | Percentage |
| Number of needs | 292 | 95.7 | 13 | 4.3 |
| Number of unmet needs (n = 272)* | 260 | 95.6 | 12 | 4.4 |
| Caregiver Needs Scale score | 273 | 89.5 | 32 | 10.5 |
| Financial problem | 283 | 92.8 | 22 | 7.2 |
| Employment problem | 299 | 98.0 | 6 | 2.0 |
| Family Support Score | 267 | 87.5 | 38 | 12.5 |

*n was derived from those who answered they had one or more needs
(no. of completers for number of needs – no. of completers who answered they did not have any needs, i.e. 292-20 = 272)

There were no differences in terms of child gender (p = 0.488), age (p = 0.280), ethnicity (p = 0.447), type of caregiver (p = 0.478) caregiver's marital status (p = 0.400), number of children (p = 0.311), number of disabled children in the family (p =

0.557) and presence of medical problem in the caregiver (p = 0.767) between those completing and those not completing the Caregiver Needs Scale. However, completers had higher education level (p = 0.003) and income level (p = 0.002) than non-completers (table 4.4). A higher percentage of caregivers with upper secondary and college or university education completed the CNS (72.9%) compared to non-completers (43.8%). After adjusting for education level, there was no longer a significant difference in income level between completers and non-completers (p = 0.154).

There were no significant differences in child age category, gender, ethnicity, type of primary caregiver, marital status of primary caregiver, number of children, number of disabled children in the family and presence of medical problem in the caregiver for all other outcome variables. However, there was a significant difference in caregiver's education level for the outcome Number of Needs. There were also significant differences in caregiver's education level and household income level between completers and non-completers for the outcomes Financial Problem and Family Support Score. Additional tables on completers and non-completers can be found in Appendix I.

Completers had higher education level and higher income level than non-completers. There is a significant correlation between education level and income level (correlation coefficient 0.584, p value <0.001). After adjusting for education level, there were no longer significant differences in income level between completers and non-completers (p = 0.884 for outcome Financial Problem and p = 0.133 for outcome FSS). Thus, it can be concluded that a systematic non-response bias exists in the sample data due to education level, which is not unexpected.

**Table 4.4:** Baseline characteristics of children with disabilities and their caregivers who completed and did not complete the Caregiver Needs Scale

| | Completers (n = 273) | | Non-completers (n = 32) | | p value | Total (n = 305) | |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | | No. | % |
| **Age category** | | | | | 0.280 | | |
| 0 – 3 years | 31 | 11.4 | 2 | 6.3 | | 33 | 10.8 |
| 4 – 6 years | 61 | 22.3 | 4 | 12.5 | | 65 | 21.3 |
| 7 – 12 years | 180 | 65.9 | 26 | 81.2 | | 206 | 67.5 |
| Not answered | 1 | 0.4 | 0 | 0 | | 1 | 0.3 |
| **Gender** | | | | | 0.488 | | |
| Male | 170 | 62.3 | 22 | 68.7 | | 192 | 63.0 |
| Female | 102 | 37.4 | 10 | 31.3 | | 112 | 36.7 |
| Not answered | 1 | 0.4 | 0 | 0 | | 1 | 0.3 |
| **Ethnicity** | | | | | | | |
| Malay | 175 | 64.1 | 18 | 56.2 | 0.447 | 193 | 63.3 |
| Chinese | 74 | 27.1 | 12 | 37.5 | | 86 | 28.2 |
| Indian | 24 | 8.8 | 2 | 6.3 | | 26 | 8.5 |
| Others | 0 | 0 | 0 | 0 | | 0 | 0 |
| **Primary caregiver** | | | | | 0.478 | | |
| Parents | 268 | 98.2 | 30 | 93.8 | | 298 | 97.7 |
| Others | 5 | 1.8 | 1 | 3.1 | | 6 | 2.0 |
| Not answered | 0 | 0 | 1 | 3.1 | | 1 | 0.3 |
| **Marital status of primary caregiver** | | | | | | | |
| Single | 1 | 0.4 | 0 | 0 | 0.400 | 1 | 0.3 |
| Married | 253 | 92.6 | 27 | 84.3 | | 280 | 91.8 |
| Widowed | 7 | 2.6 | 0 | 0 | | 7 | 2.3 |
| Separated/divorced | 7 | 2.6 | 2 | 6.3 | | 9 | 3.0 |
| Not relevant (not parents) | 5 | 1.8 | 1 | 3.1 | | 6 | 2.0 |
| Not answered | 0 | 0 | 2 | 6.3 | | 2 | 0.7 |

Table 4.4, continued

| | Completers (n = 273) | | Non-completers (n = 32) | | p value | Total (n = 305) | |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | No. |
| **Primary caregiver's highest education** (mother/father or other caregiver) | | | | | **0.003** | | |
| No education | 3 | 1.1 | 1 | 3.1 | | 4 | 1.3 |
| Primary | 19 | 7.0 | 3 | 9.4 | | 22 | 7.2 |
| Lower secondary | 52 | 19.0 | 13 | 40.6 | | 65 | 21.3 |
| Upper secondary | 135 | 49.5 | 12 | 37.5 | | 147 | 48.2 |
| College/University | 64 | 23.4 | 2 | 6.3 | | 66 | 21.6 |
| Not answered | 0 | 0 | 1 | 3.1 | | 1 | 0.3 |
| **Income category of household** | | | | | **0.002** | | |
| <RM2000/month | 148 | 54.2 | 26 | 81.3 | | 174 | 57.0 |
| RM2000 – 3999/month | 79 | 28.9 | 5 | 15.6 | | 84 | 27.5 |
| ≥RM4000/month | 37 | 13.6 | 0 | 0 | | 37 | 12.1 |
| Not answered | 9 | 3.3 | 1 | 3.1 | | 10 | 3.3 |
| **No. of children** | | | | | 0.311 | | |
| 1 – 2 | 115 | 42.1 | 11 | 34.4 | | 126 | 41.3 |
| 3 – 4 | 110 | 40.3 | 11 | 34.4 | | 121 | 39.7 |
| ≥5 | 41 | 15.0 | 8 | 25.0 | | 49 | 16.0 |
| Not answered | 7 | 2.6 | 2 | 6.2 | | 9 | 3.0 |
| **No. of disabled children in the family** | | | | | 0.557 | | |
| Two or more | 32 | 11.7 | 5 | 15.6 | | 37 | 12.1 |
| One | 234 | 85.7 | 25 | 78.1 | | 259 | 84.9 |
| Not answered | 7 | 2.6 | 2 | 6.3 | | 9 | 3.0 |
| **Caregiver has medical problem** | | | | | 0.767 | | |
| Yes | 79 | 28.9 | 8 | 25.0 | | 87 | 28.5 |
| No | 191 | 70.0 | 22 | 68.8 | | 213 | 69.8 |
| Not answered | 3 | 1.1 | 2 | 6.2 | | 5 | 1.7 |

**Table 4.5:** Comparison of ABILITIES Index score between completers and non-completers of the Caregiver Needs Scale

| | Completers (n = 273) | | | Non-completers (n = 32) | | | p value | Total (n = 305) | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Mean (SD) | Median | % with moderate, severe and profound problem | Mean (SD) | Median | % with moderate, severe and profound problem | | Mean (SD) | Median | % with moderate, severe and profound problem |
| Overall | 42.0 (17.3) | 36.0 | | 40.6 (13.4) | 36.5 | | 0.841 | 41.9 (17.1) | 36.0 | |
| Hearing | 1.7 (1.4) | 1 | 12.4 | 3.4 (2.2) | 4 | 25.1 | **<0.001** | 1.8 (1.5) | 1 | 13.8 |
| Behaviour and social skills | 2.8 (1.6) | 2.5 | 34.8 | 3.0 (1.6) | 3 | 18.8 | 0.540 | 2.8 (1.6) | 2.5 | 33.1 |
| Intellectual functioning | 3.0 (1.7) | 3 | 39.3 | 3.0 (1.8) | 3 | 18.8 | 0.940 | 3.0 (1.7) | 3 | 37.1 |
| Limb functioning | 2.1 (1.5) | 1 | 18.3 | 1.6 (1.2) | 1 | 6.3 | 0.191 | 2.0 (1.5) | 1 | 17.0 |
| Intentional communication | 3.0 (1.6) | 3 | 42.1 | 3.1 (1.8) | 3 | 18.8 | 0.928 | 3.0 (1.6) | 3 | 39.7 |
| Tonicity | 2.2 (1.6) | 1 | 21.7 | 2.1 (1.4) | 1 | 12.5 | 0.848 | 2.2 (1.6) | 1 | 20.7 |
| General health | 2.1 (1.5) | 1 | 19.8 | 2.0 (1.2) | 1 | 6.3 | 0.832 | 2.1 (1.5) | 1 | 18.4 |
| Vision | 1.9 (1.4) | 1 | 16.4 | 1.4 (1.2) | 1 | 3.1 | 0.134 | 1.8 (1.4) | 1 | 15.1 |
| Body structure | 2.0 (1.5) | 1 | 17.5 | 1.4 (0.7) | 1 | 0 | 0.145 | 2.0 (1.4) | 1 | 15.7 |

Completers and non-completers of all outcome variables did not differ in their scoring of the ABILITIES Index except for hearing score (table 4.5 and Appendix I). Non-completers reported significantly higher severity of hearing impairment than completers of the Caregiver Needs Scale (median 4 vs 1, p <0.001), Number of Unmet Needs (median 3.5 vs 1, p = 0.002) and Family Support Score (median 1.5 vs 1, p = 0.009).

## 4.3 Child's health care service needs and unmet needs

### 4.3.1 Distribution of child's needs and unmet needs

As a whole, children with disabilities needed an average of 5.1 ± 3.0 services/assistive devices. Overall, the number of services/assistive devices not fully received ranged from 0 – 15, mean 2.7 ± 2.5 and median 2.0, while the number of services/assistive devices not received at all ranged from 0 – 9, mean 1.4 ± 1.8 and median 1.0.

The service that was needed most was the service of a specialist doctor, followed by speech therapist and occupational therapist (table 4.6). More than 50% of children needed those services. The least needed services were physiotherapy and home nursing. Approximately 50% of children needed dental services and approximately a quarter needed psychological services. For assistive devices, communication aids were the most needed.

More than 60% of children had unmet needs for dietary advice and psychological services, while more than 50% had unmet needs for dental services, speech therapy and home nursing care. The services least unmet were hearing related services and services of a specialist doctor. In regards to assistive devices, home modifications and communication aids were the most unmet. More than half the children also had an unmet need for mobility aids and vision aids. Disposable medical items such as syringes

and catheters, and special medical equipment such as portable ventilators and suction machines, were more readily obtained.

**Table 4.6:** Distribution of need and unmet need for specific services/assistive devices

| | Percentage that need (95% CI) | Unweighted count | Percentage of unmet need (95% CI) | Unweighted count |
|---|---|---|---|---|
| **Services** | | | | |
| Specialist doctor | 67.8 (61.4, 73.7) | 220 | 37.8 (30.6, 45.7) | 78 |
| Speech therapy | 56.9 (50.5, 63.0) | 162 | 56.8 (47.9, 65.2) | 84 |
| Occupational therapy | 56.4 (50.0, 62.5) | 167 | 44.5 (35.9, 53.4) | 71 |
| Dental services | 49.6 (43.1, 56.0) | 154 | 59.9 (50.8, 68.4) | 86 |
| Dietary/nutritional advice | 30.9 (25.3, 37.1) | 100 | 63.3 (51.8, 73.4) | 58 |
| Vision related services | 27.8 (22.7, 33.5) | 97 | 48.6 (37.0, 60.4) | 44 |
| Hearing related services | 27.6 (22.5, 33.3) | 102 | 38.1 (27.4, 50.1) | 31 |
| Psychology services | 25.5 (20.1, 31.8) | 62 | 63.0 (48.8, 75.3) | 38 |
| Physiotherapy | 22.6 (18.9, 26.9) | 106 | 41.5 (30.9, 53.1) | 42 |
| Home nursing services | 2.6 (1.3, 5.2) | 11 | 53.5 (12.0, 90.7) | 6 |
| **Assistive devices** | | | | |
| Communication aids | 33.0 (27.1, 39.4) | 97 | 79.2 (69.0, 86.7) | 72 |
| Vision aids | 16.6 (12.5, 21.6) | 57 | 52.7 (37.4, 67.5) | 34 |
| Mobility aids | 11.6 (9.9, 13.6) | 68 | 55.6 (43.2, 67.4) | 38 |
| Hearing aids | 8.5 (6.5, 10.9) | 46 | 34.2 (19.8, 52.3) | 13 |
| Disposable medical items | 4.3 (2.7, 6.9) | 21 | 27.2 (13.2, 47.9) | 7 |
| Home modifications | 3.5 (2.1, 5.7) | 18 | 80.6 (55.3, 93.3) | 14 |
| Special medical equipment | 2.1 (1.0, 4.2) | 10 | 23.8 (5.3, 63.6) | 3 |

*Unmet need is defined as not fully receiving a needed service (receiving the service partially and not receiving the service at all)

**Table 4.7:** Distribution of receipt of services/assistive devices among those who need

| | Received fully | | Received partially | | Not received at all | | Not answered | |
|---|---|---|---|---|---|---|---|---|
| | % | 95% CI | % | 95% CI | % | 95% CI | % | 95% CI |
| **Services** | | | | | | | | |
| Specialist doctor | **59.0** | 51.1, 66.4 | **28.7** | 22.2, 36.3 | **9.1** | 5.3, 15.1 | **3.2** | 1.3, 7.7 |
| Speech therapy | **39.4** | 31.3, 48.2 | **32.9** | 25.0, 41.9 | **23.8** | 17.1, 32.2 | **3.8** | 1.5, 9.2 |
| Occupational therapy | **53.3** | 44.5, 62.0 | **26.6** | 19.5, 35.2 | **17.9** | 12.0, 25.8 | **2.2** | 0.8, 6.1 |
| Dental services | **38.3** | 29.9, 47.4 | **31.1** | 23.2, 40.3 | **28.8** | 21.0, 38.1 | **1.8** | 0.5, 6.7 |
| Dietary/ nutritional advice | **29.8** | 20.8, 40.8 | **29.3** | 19.7, 41.2 | **34.0** | 23.8, 45.9 | **6.9** | 2.7, 16.3 |
| Vision related services | **41.6** | 30.9, 53.2 | **33.1** | 22.8, 45.4 | **15.5** | 8.7, 26.0 | **9.8** | 4.3, 20.7 |
| Hearing related services | **54.1** | 42.7, 65.1 | **24.5** | 15.4, 36.6 | **13.6** | 7.0, 24.8 | **7.8** | 3.1, 18.1 |
| Psychology services | **32.0** | 20.5, 46.2 | **30.1** | 18.8, 44.4 | **33.0** | 21.2, 47.3 | **5.0** | 1.4, 16.3 |
| Physiotherapy | **56.9** | 45.4, 67.7 | **27.2** | 18.1, 38.8 | **14.3** | 8.0, 24.3 | **1.5** | 0.4, 6.0 |
| Home nursing services | **46.5** | 9.3, 88.0 | **27.5** | 2.9, 82.8 | **26.1** | 9.8, 53.4 | **0** | |
| **Assistive devices** | | | | | | | | |
| Communication aids | **17.1** | 10.3, 27.0 | **17.5** | 10.2, 28.3 | **61.7** | 50.1, 72.1 | **3.7** | 1.3, 10.2 |
| Vision aids | **45.4** | 30.9, 60.8 | **10.0** | 3.6, 25.1 | **42.7** | 28.9, 57.6 | **1.9** | 0.5, 6.3 |
| Mobility aids | **44.4** | 32.6, 56.8 | **11.8** | 5.9, 22.2 | **43.9** | 32.2, 56.3 | **0** | |
| Hearing aids | **60.3** | 42.3, 75.8 | **15.9** | 5.6, 37.6 | **18.3** | 7.4, 38.7 | **5.5** | 1.7, 16.1 |
| Disposable medical items | **76.2** | 36.4, 94.7 | **15.6** | 2.3, 59.1 | **8.2** | 0.6, 56.1 | **0** | |
| Home modifications | **19.4** | 6.7, 44.7 | **25.4** | 13.8, 42.2 | **55.2** | 34.5, 74.2 | **0** | |
| Special medical equipment | **76.2** | 36.4, 94.7 | **15.6** | 2.3, 59.1 | **8.2** | 0.6, 56.1 | **0** | |

Table 4.7 and figure 4.1 shows the receipt of needed services/assistive devices; whether they were received fully (met need), partially or not at all (unmet need). Services usually not received were dietary/nutritional advice, psychology services, dental services and speech therapy, while assistive devices usually not received were communication aids, home modifications, mobility aids and vision aids.

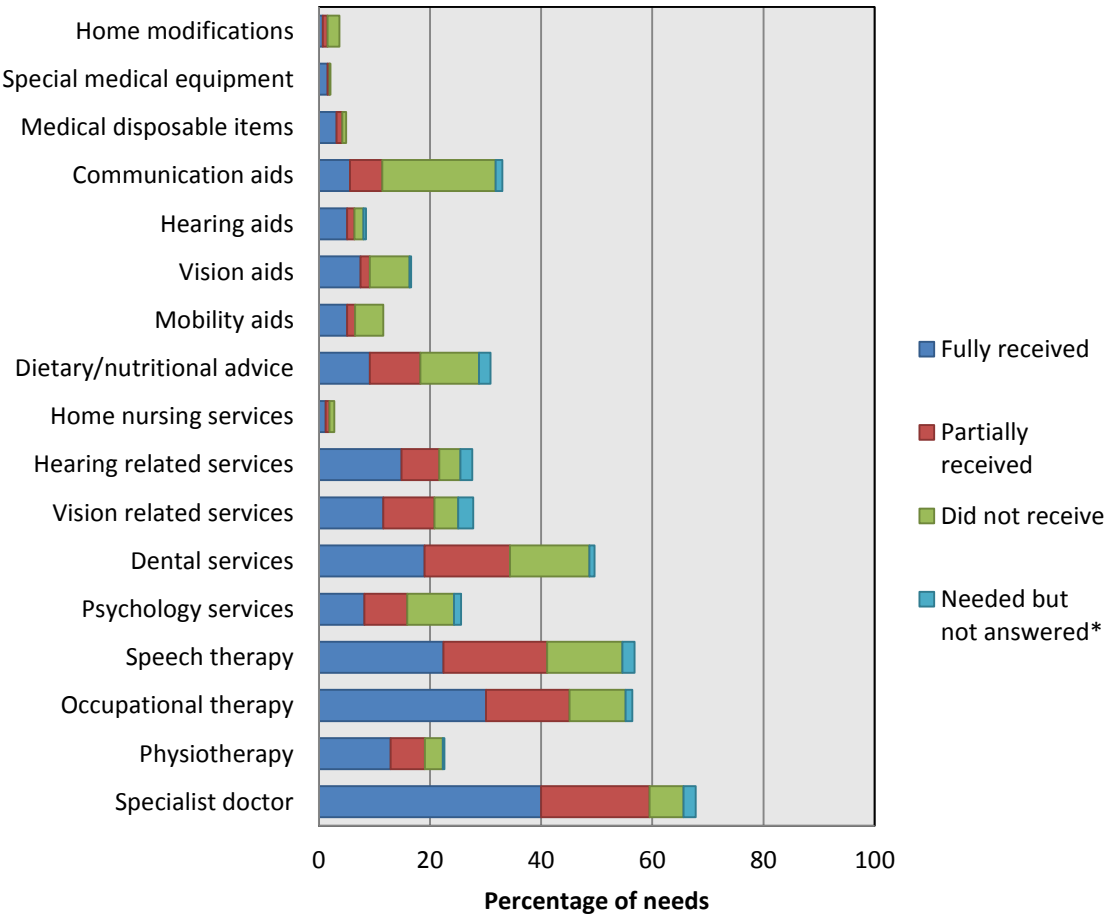


**Figure 4.1:** Caregiver perception of services/assistive devices needed and received

*Caregivers reported their child needed the service but did not report whether their child received it or not

Note: Findings on education support needs can be found in Appendix J.

### 4.3.2 Needs and unmet needs by disability category

Disability category was grouped into Learning, Multiple and Others (vision, hearing, speech and physical disability) for sub-analysis.

Children with learning disability and with sole physical, vision, hearing or speech disability needed an average of 4 services/assistive devices while children with multiple disabilities needed an average of 7 services/assistive devices (table 4.8).

**Table 4.8:** Distribution of number of needs and unmet needs by disability category

| Need and unmet need for services/assistive devices | Learning Mean (SD) | Multiple Mean (SD) | Others Mean (SD) |
|---|---|---|---|
| Number needed | 4.2 (0.5) | 7.3 (0.6) | 4.3 (0.6) |
| Number fully received | 1.9 (0.4) | 4.1 (0.7) | 2.5 (0.5) |
| **Number not fully received** | 2.7 (0.5) | 3.4 (0.7) | 2.1 (0.4) |
| Number partially received | 1.5 (0.4) | 1.7 (0.5) | 1.0 (0.3) |
| Number not received at all | 1.3 (0.4) | 1.8 (0.5) | 1.1 (0.3) |

Children with learning disability had an average of 2 – 3 services/assistive devices unmet, while children with multiple disabilities and children with other disabilities had around 3 and 2 services/assistive devices unmet respectively.

A higher percentage of children with learning disability had high level of unmet needs, while a higher percentage of children with multiple disabilities and other disabilities had low or moderate level of unmet needs (table 4.9).

**Table 4.9:** Distribution of level of unmet needs by disability category

| Level of unmet needs | Learning | | | Multiple | | | Others | | |
|---|---|---|---|---|---|---|---|---|---|
| | % | 95% CI | Unweighted count | % | 95% CI | Unweighted count | % | 95% CI | Unweighted count |
| Low | 30.1 | 22.0, 39.7 | 31 | 36.4 | 26.3, 47.7 | 28 | 39.5 | 29.2, 50.7 | 32 |
| Moderate | 26.2 | 18.6, 35.6 | 27 | 33.8 | 24.0, 45.1 | 26 | 30.8 | 21.5, 42.0 | 25 |
| High | 43.7 | 34.4, 53.5 | 45 | 29.9 | 20.6, 41.1 | 23 | 29.7 | 20.5, 40.8 | 23 |

In the study sample, it was found that 40.5% of children with learning disability had behaviour and social skills problem, while 47.6% had communication problems.

Among those with learning disability, 31.0% (95% CI 23.4, 39.6) of children needed psychology services but 64.1% (95% CI 47.4, 78.0) of those that needed it did not fully receive this service (table 4.10). In addition, 34.1% (95% CI 26.3, 42.9) of children with learning disability needed communication aids but 83.7% (95% CI 68.9, 92.3) of them had this need unmet.

More than 50% of children with multiple disabilities needed physiotherapy, occupational therapy, speech therapy, dental services, dietary or nutritional advice and mobility aids. Unfortunately, more than half of those who needed dietary or nutritional advice and mobility aids did not have these needs met.

**Table 4.10:** Distribution of need and unmet need in children with learning disability and children with multiple disabilities

| | Learning disability | | | | Multiple disabilities | | | |
|---|---|---|---|---|---|---|---|---|
| Type of service/ assistive device | % that need | 95% CI | % unmet | 95% CI | % that need | 95% CI | % unmet | 95% CI |
| Specialist doctor | 62.7 | 53.9, 70.7 | 40.5 | 30.2, 51.8 | 89.3 | 80.6, 94.4 | 30.7 | 21.2, 42.1 |
| Occupational therapy | 57.9 | 49.1, 66.3 | 46.6 | 35.2, 58.3 | 81.0 | 71.0, 88.0 | 36.8 | 26.0, 49.1 |
| Speech therapy | 61.1 | 52.3, 69.3 | 61.0 | 49.5, 71.5 | 61.9 | 51.0, 71.7 | 48.1 | 34.5, 61.9 |
| Psychology services | 31.0 | 23.4, 39.6 | 64.1 | 47.4, 78.0 | 19.0 | 12.0, 29.0 | 56.3 | 31.2, 78.5 |
| Dental services | 48.4 | 39.8, 57.2 | 63.9 | 51.0, 75.1 | 64.3 | 53.4, 73.9 | 44.4 | 31.7, 58.0 |
| Dietary/nutritional advice | 28.6 | 21.3, 37.1 | 69.4 | 52.3, 82.5 | 51.2 | 40.5, 61.8 | 55.8 | 40.5, 70.1 |
| Communication aids | 34.1 | 26.3, 42.9 | 83.7 | 68.9, 92.3 | 39.3 | 29.4, 50.2 | 75.8 | 57.9, 87.6 |
| Physiotherapy | - | - | - | - | 82.1 | 72.4, 89.0 | 34.8 | 24.3, 47.0 |
| Mobility aids | - | - | - | - | 63.1 | 52.2, 72.8 | 52.8 | 39.1, 66.1 |
| Vision related services | - | - | - | - | 50.0 | 39.4, 60.6 | 38.1 | 24.5, 53.8 |
| Vision aids | - | - | - | - | 21.4 | 13.9, 31.6 | 77.8 | 52.1, 91.9 |
| Hearing related services | - | - | - | - | 38.1 | 28.3, 49.0 | 21.9 | 10.6, 39.9 |
| Hearing aids | - | - | - | - | 9.5 | 4.8, 18.0 | 62.5 | 25.6, 89.0 |

Children with multiple disabilities need the service of a specialist doctor, occupational therapy, dental services and dietary advice more than children with learning disability, while need for speech therapy and communication aids was almost the same (figure 4.2). However, children with learning disability needed psychology services more. Although children with multiple disabilities needed more services/assistive devices, children with learning disability consistently showed higher percentages of unmet need for all relevant services/assistive devices.

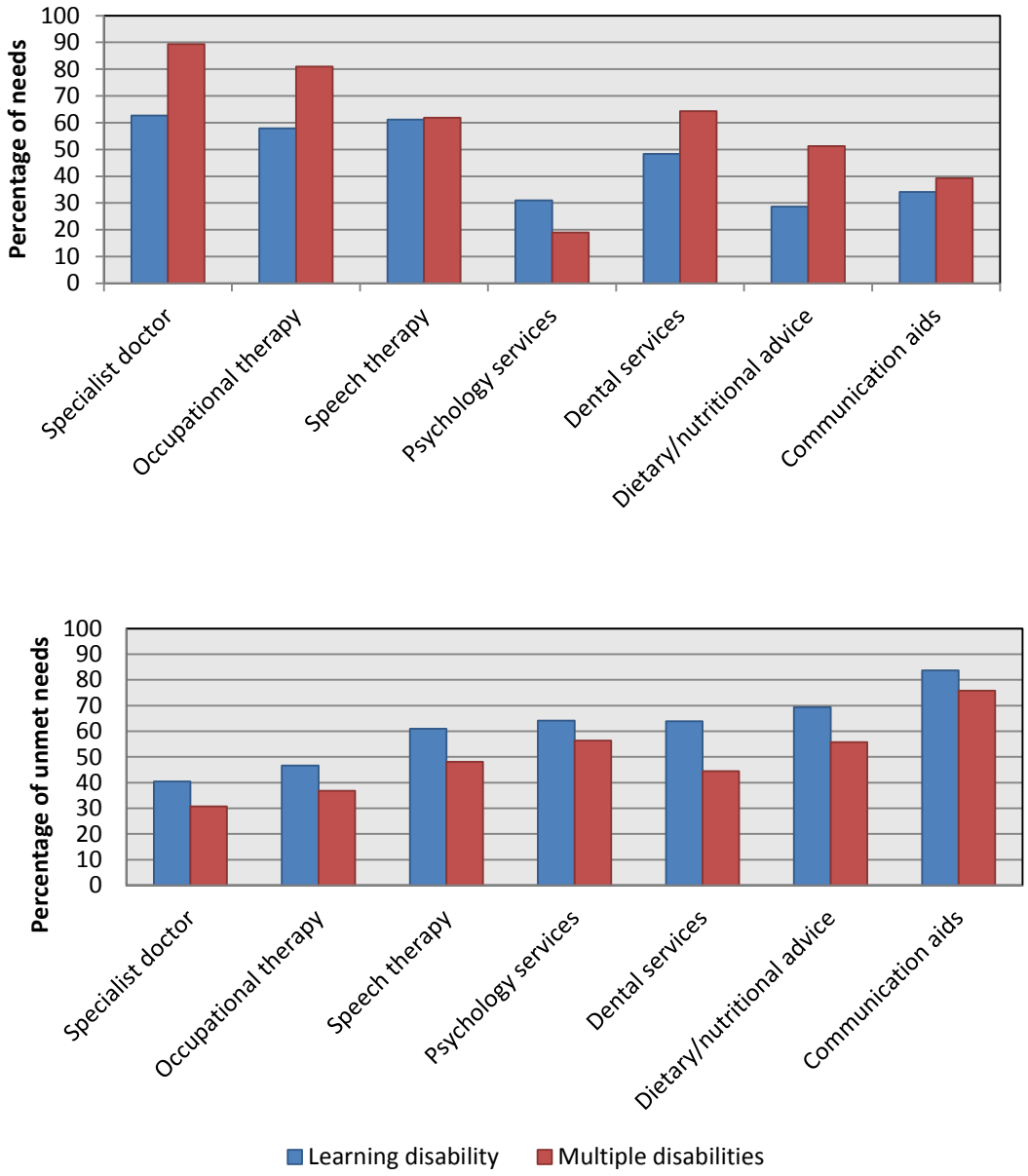


**Figure 4.2:** Distribution of needs and unmet needs for specific services in children with learning disability and multiple disabilities

To see whether children with particular impairments receive services that are aimed at reducing the impact of their resulting disability, further sub-analysis was done by categorizing children according to the disability which is likely to benefit from a specific service or assistive device (refer to Appendix K for more details).

Psychological services are usually needed by children who have behaviour and social skills problem. Only 33.9% (95% CI 24.1, 45.3) of caregivers who perceived their child to have a behavioural or social skills problem felt their child needed psychological services. Out of this, 75.3% (95% CI 55.2, 88.3) did not have this need met.

A higher percentage of children with multiple disabilities needed physiotherapy compared to children with physical disability. Unmet need for physiotherapy was 47.6% (95% CI 27.2, 68.8) for children with physical disability and 34.8% (95% CI 24.3, 46.9) for children with multiple disabilities.

Children with multiple disabilities also needed mobility aids more than children with physical disability. Unmet need for mobility aids was 69.2% (95% CI 39.2, 88.7) for children with physical disability and 52.8% (95% CI 39.1, 72.8) for children with multiple disabilities.

It was found that 70% (95% CI 53.7, 82.5) of children with hearing or speech disability needed speech therapy and 32% (95% CI 17.7, 50.8) of them had this need unmet. Besides that, 37.6% (95% CI 24.1, 53.3%) of these children needed communication aids and 53.3% (95% CI 28.3, 76.8) of them had this need unmet.

Need for speech therapy was reported by 75% (95% CI 65.5, 82.5) of caregivers who perceived their child to have a communication problem and 64.6% (95% CI 53.0, 74.7) did not have this need met. In addition, 47.1% (95% CI 37.1, 57.3) of caregivers who

perceived their child to have a communication problem felt their child needed communication aids, and 82.7% (95% CI 69.1, 91.1) did not have this need met.

Out of children with visual disability, 94.1% (95% CI 66.4, 99.2) needed vision related services and 50.0% (95% CI 26.4, 73.6) of them had this need unmet, while 70.6% (95% CI 44.9, 97.6) needed vision aids and approximately two thirds of them had this need unmet.

As for children with hearing disability, 94.7% (95% CI 80.9, 98.7) needed hearing related services and 22.2% (95% CI 11.3, 39.0) did not have this need met, while 89.5% (95% CI 74.9, 96.1) needed hearing aids and 17.6% (95% CI 7.9, 35.0) of them did not have this need met.

### 4.4 Determinants of needs and unmet needs

#### 4.4.1 Child and family characteristics predisposing to having more health care service needs

In bivariate analysis, category of disability, age, education level of primary caregiver, income level and severity of disability were found to be associated with number of needs (table 4.11). There was no difference in reported needs between the ethnicities.

By looking at whether the estimated mean falls within the 95% confidence interval of the other categories in the independent variable, it is possible to see where the differences lie between the respective categories. An example of the interpretation is given for the independent variable "disability category" and the same interpretation follows for the other independent variables.

The unadjusted mean for the category "multiple disabilities" (7.31) falls outside the 95% CI for "learning disability" (3.70, 4.60) and "other disability" (3.78, 4.89). The unadjusted mean for the category "learning disability" (4.15) falls outside the 95% CI for "multiple disabilities" (6.69, 7.93) and the unadjusted mean for "other disability" (4.34) also fall outside the 95% CI for "multiple disabilities" (6.69, 7.93). This shows that there is a significant difference in the mean number of needs between children with multiple disabilities and children with learning disability and other disability. Children with multiple disabilities had higher unadjusted mean number of needs compared to children with learning disability and other disability.

However, the unadjusted mean for "learning disability" (4.15) falls inside the 95% CI for "other disability" (3.78, 4.89) and the unadjusted mean for "other disability" (4.34) falls inside the 95% CI for "learning disability" (3.70, 4.60), indicating that there is no significant difference in the mean number of needs between learning disability and other disability categories.

The p value for the test of significance for “disability category” overall was <0.001. The p value for the test of significance between “learning disability” and “other disability”, which is the reference category, was 0.607, whereas the p value between “multiple disabilities” and “other disability was <0.001. The p value for the test of significance between “learning disability” and “multiple disabilities” is not shown but interpretation of significant difference can be derived from examination of the mean estimate and 95% CIs. The $R^2$ for disability category is 0.157, meaning that 15.7% of the variance in number of needs was explained by disability category.

Although the p value for income category overall was >0.05 in bivariate analysis, examination of the unadjusted mean estimates and their 95% CIs reveal that caregivers in households with income in the bottom 40% reported lower number of needs compared to caregivers in households with income in the middle 40% and top 20%, before adjustment for other variables. After the variables were entered into a multivariate model, income level no longer predicted the number of child needs.

Disability category, age category, education level of primary caregiver and severity of disability were associated with number of needs, after adjustment for other variables (table 4.11). $R^2$ for the multivariate model is 0.293, meaning that 29.3% of the variance in number of needs was explained by the model.

Children with multiple disabilities had more needs compared to children with learning disabilities and children with solely vision, hearing, speech or physical disability. There was no difference in the number of needs between children with learning disabilities and children with other disabilities.

**Table 4.11:** Factors associated with mean number of needs

| | Unadjusted mean | 95% CI | p value | $R^2$ | Adjusted mean | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Disability category** | | | <0.001 | 0.157 | | | 0.021 |
| Learning | 4.15 | 3.70, 4.60 | 0.607 | | 5.09 | 4.59, 5.59 | 0.362 |
| Multiple | 7.31 | 6.69, 7.93 | **<0.001** | | 6.42 | 5.54, 7.30 | **0.006** |
| Others† | 4.34 | 3.78, 4.89 | | | 4.76 | 4.08, 5.45 | |
| **Age** | | | **<0.001** | 0.086 | | | **0.001** |
| 0 – 3 | 6.06 | 4.97, 7.14 | 0.002 | | 5.77 | 4.90, 6.63 | 0.022 |
| 4 – 6 | 6.01 | 5.47, 6.55 | <0.001 | | 5.85 | 5.27, 6.43 | 0.001 |
| 7 – 12† | 4.17 | 3.75, 4.58 | | | 4.65 | 4.23, 5.08 | |
| **Ethnicity** | | | 0.895 | 0.001 | | | - |
| Indian | 4.47 | 3.09, 5.86 | 0.750 | | - | - | - |
| Chinese | 4.55 | 3.89, 5.21 | 0.692 | | - | - | - |
| Malay† | 4.71 | 4.29, 5.13 | | | - | - | |
| **Education level of primary caregiver** | | | 0.002 | 0.050 | | | 0.102* |
| None, primary or lower secondary | 3.74 | 3.13, 4.34 | **0.002** | | **4.81** | **3.98, 5.64** | 0.125 |
| Upper secondary | 5.00 | 4.51, 5.48 | 0.593 | | **5.71** | **5.14, 6.29** | 0.937 |
| Tertiary† | 5.23 | 4.52, 5.94 | | | **5.75** | **5.00, 6.51** | |
| **Income category** | | | 0.071 | 0.023 | | | 0.770 |
| Bottom 40% | 4.23 | 3.64, 4.82 | **0.030** | | 5.30 | 4.65, 5.94 | 0.527 |
| Middle 40% | 4.95 | 4.44, 5.47 | 0.528 | | 5.30 | 4.76, 5.84 | 0.475 |
| Top 20%† | 5.23 | 4.55, 5.91 | | | 5.68 | 4.78, 6.58 | |
| **ABILITIES Index score**‡ | 0.082 | 0.060, 0.103 | **<0.001** | 0.196 | 0.048 | 0.019, 0.077 | **0.001** |

†Reference category ‡Parameter estimates presented instead of mean

* p>0.05 but mean does not fall in the 95% CI of the other categories

In the multivariate model, the $R^2$ is 0.293 and the no. of respondents = 242

Children aged 0 – 3 years had more needs compared to children aged 7 – 12 years. Children aged 4 – 6 years also had more needs compared to children aged 7 – 12 years. There was no difference in the number of needs between children aged 0 – 3 years and children aged 4 – 6 years. In summary, children who are not of school going age had more needs compared to children of school going age. More needs were reported if the child had a higher ABILITIES Index score, indicating worse severity of the child's disability.

Caregivers with none, primary or lower secondary education reported less needs compared to caregivers with upper secondary education and caregivers with tertiary education. The mean for the first category does not fall in the 95% confidence interval of the second and third categories and vice versa. There was no difference in reported needs between caregivers with upper secondary education and tertiary education. In summary, caregivers with upper secondary education or higher, reported more needs.

There was no difference in reported needs between the income groups, after adjustment for other variables. Income level and education level are significantly correlated. Families with higher income had higher education ($r = 0.584$). To test whether the association between income level and number of needs could be explained by education level, sensitivity analysis was performed.

When education level was entered into the model, while adjusting for disability category, age and ABILITIES Index score, the findings were similar with the multivariate analysis results adjusted for all factors ($p = 0.071$ but mean for none, primary and lower secondary did not fall in the 95% CI of the other categories and vice versa). When income level was entered into the model, while adjusting for disability category, age and ABILITIES Index score, the findings were similar with the income level bivariate analysis results ($p = 0.218$, mean for the bottom 40% did not fall in the

95% CI of the top 20% and vice versa). Income level was no longer associated with number of needs after adjusted for education level.

### 4.4.2 Child and family characteristics predisposing to having more unmet health care service needs

Unmet need was defined as not fully receiving a specific service that was needed. Referring to table 4.12, 23.5% of children did not have any unmet needs and 76.5% had one or more unmet needs.

**Table 4.12:** Distribution of number of unmet needs (number of services not fully received)

| No. of unmet needs | Frequency | Percentage |
|---|---|---|
| 0 | 61 | 23.5 |
| 1 | 34 | 13.1 |
| 2 | 44 | 16.9 |
| 3 | 36 | 13.8 |
| 4 | 28 | 10.8 |
| 5 | 23 | 8.8 |
| 6 | 13 | 5.0 |
| 7 | 8 | 3.1 |
| 8 | 6 | 2.3 |
| 9 | 4 | 1.5 |
| 10 | 2 | 0.8 |
| 15 | 1 | 0.4 |
| Total | 260* | 100.0 |

*Out of 272 respondents who reported they had one or more service needs, 260 completed the questions for outcome no. of unmet needs.

Level of unmet needs was derived from the ratio of number of unmet needs (number not fully received) to the number of needs. From the distribution (table 4.13), 28.1% (95% CI 22.3, 34.9) had moderate level of unmet needs and 39.3% (95% CI 32.5, 46.4) had high level of unmet needs.

**Table 4.13:** Distribution of level of unmet needs

| Level of unmet needs | Estimate percentage | 95% CI | Unweighted count |
|---|---|---|---|
| Low | 32.6 | 26,4, 39.5 | 91 |
| Moderate | 28.1 | 22.3, 34.9 | 78 |
| High | 39.3 | 32.5, 46.4 | 91 |
| Total | | | 260 |

In bivariate analysis, age of the child was associated with level of unmet needs (table 4.14). Children aged 0 – 3 years had lower level of unmet needs compared to children aged 7 – 12 years (Unadjusted OR 0.33, 95% CI 0.12, 0.91). Having two or more disabled child in the family was also associated with having lower level of unmet needs (Unadjusted OR 0.56, 95% CI 0.35, 0.90).

Type of disability and severity of disability, as measured by the ABILITIES Index score, were not associated with unmet needs. There was also no association between ethnicity, primary caregiver's education level, family income level, number of children in the family and whether the caregiver had a medical problem with level of unmet needs. The number of services needed was not associated with level of unmet needs as well.

Disability category, age of the child, ethnicity, and number of disabled child in the family were entered into multivariate analysis. The pseudo $R^2$ for the multivariate model is 0.085, meaning only 8.5% of the variance in level of unmet needs is explained

by the model. Age of the child (0 – 3 years vs 7 – 12 years) and having more than one disabled child in the family remained associated with lower level of unmet needs.

Other variables did not reach statistically significant difference, although there were certain trends seen. Children with learning disability and children who had caregivers with medical problem showed a trend towards having higher level of unmet needs. The lower limit of their 95% confidence intervals was near to 1 and the upper limit was >2.0. Higher education of the primary caregiver, lower income and having more children also showed a trend towards increasing the odds of reporting higher level of unmet needs.

**Table 4.14:** Factors associated with level of unmet needs

| | Unadjusted OR | 95% CI | p value | Pseudo $R^2$ | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Threshold** | | | | | | | |
| Low unmet needs | | | | | 0.39 | 0.21, 0.71 | 0.003 |
| Moderate unmet needs | | | | | 1.34 | 0.75, 2.42 | 0.321 |
| **Disability category** | | | 0.132 | 0.016 | | | 0.036 |
| Learning | 1.67 | 0.97, 2.88 | 0.066 | | 1.48 | 0.81, 2.71 | 0.203 |
| Multiple | 1.08 | 0.62, 1.87 | 0.793 | | 1.02 | 0.56, 1.87 | 0.949 |
| Others† | 1 | | | | 1 | | |
| **Age** | | | 0.096 | 0.029 | | | 0.090 |
| 0 – 3 | 0.33 | 0.12, 0.91 | **0.032** | | 0.29 | 0.09, 0.92 | **0.036** |
| 4 – 6 | 0.81 | 0.46, 1.42 | 0.455 | | 0.70 | 0.38, 1.28 | 0.240 |
| 7 – 12† | 1 | | | | 1 | | |
| **Ethnicity** | | | 0.224 | 0.019 | | | 0.252 |
| Indian | 0.39 | 0.13, 1.13 | 0.083 | | 0.36 | 0.11, 1.21 | 0.097 |
| Chinese | 0.90 | 0.50, 1.63 | 0.730 | | 0.89 | 0.48, 1.66 | 0.718 |
| Malay† | 1 | | | | 1 | | |

Table 4.14, continued

| | Unadjusted OR | 95% CI | p value | Pseudo $R^2$ | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Education level of primary caregiver** | | | 0.504 | 0.009 | | | - |
| None, primary or lower secondary | 0.65 | 0.31, 1.35 | 0.647 | | - | - | - |
| Upper secondary | 0.75 | 0.37, 1.49 | 0.745 | | - | - | - |
| Tertiary† | 1 | | | | - | - | |
| **Income category** | | | 0.604 | 0.006 | | | - |
| Bottom 40% | 0.99 | 0.48, 2.06 | 0.982 | | - | - | - |
| Middle 40% | 0.75 | 0.35, 1.61 | 0.459 | | - | - | - |
| Top 20%† | 1 | | | | - | - | |
| **Number of children** | | | 0.555 | 0.007 | | | - |
| 1 - 2 children | 0.73 | 0.35, 1.53 | 0.408 | | - | - | - |
| 3 - 4 children | 0.98 | 0.46, 2.09 | 0.963 | | - | - | - |
| ≥5 children† | 1 | | | | - | - | |
| **Number of disabled child** | | | | | | | |
| Two or more | 0.56 | 0.35, 0.90 | **0.016** | 0.014 | 0.48 | 0.28, 0.84 | **0.010** |
| One† | 1 | | | | 1 | | |
| **Caregiver has medical problem** | | | | | | | |
| Yes | 1.29 | 0.74, 2.23 | 0.369 | 0.004 | - | - | - |
| No† | 1 | | | | - | - | |
| **ABILITIES Index score** | 1.00 | 0.98, 1.01 | 0.604 | 0.001 | - | - | - |
| **Number of services needed** | 1.01 | 0.91, 1.11 | 0.867 | 0 | - | - | - |

†Reference category

In the multivariate model, the pseudo $R^2$ is 0.085 and the no. of respondents = 252

Another method of analysis using a different definition of 'unmet needs' was conducted, whereby the sample was grouped into those who did not receive a needed service at all and those who received a service partially or fully. The ratio of number of services not received at all to the number of services needed was calculated. From here, children were grouped into "Received needed services" and "Did not receive needed services".

Approximately half of the children received needed services while the other half did not receive needed services at all (table 4.15).

**Table 4.15:** Distribution of children by receipt of needed services

| Receipt of needed services | Estimate percentage | 95% CI | Unweighted count |
|---|---|---|---|
| Yes | 49.8 | 42.7, 56.8 | 126 |
| No | 50.2 | 43.2, 57.3 | 134 |
| Total | | | 260 |

Age of the child and number of services needed were associated with non-receipt of needed services (table 4.16). In the multivariate model, children aged 4 – 6 years and 7 – 12 years had higher odds of not receiving needed services compared to children aged 0 – 3 years. Having higher number of service needs was also associated with not receiving needed services.

**Table 4.16:** Factors associated with not receiving needed services

| | Unadjusted OR | 95% CI | p value | Pseudo $R^2$ | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Disability category** | | | 0.377 | 0.007 | | | - |
| Learning | 0.97 | 0.54, 1.76 | 0.928 | | - | - | - |
| Multiple | 1.45 | 0.76, 2.76 | 0.255 | | - | - | - |
| Others† | 1 | | | | - | - | |
| **Age** | | | 0.169 | 0.019 | | | 0.030 |
| 0 – 3 | 0.47 | 0.19, 1.17 | 0.105 | | 0.26 | 0.10, 0.70 | **0.008** |
| 4 – 6 | 1.27 | 0.63, 2.56 | 0.509 | | 0.80 | 0.36, 1.81 | 0.597 |
| 7 – 12† | 1 | | | | 1 | | |
| **Ethnicity** | | | 0.311 | 0.016 | | | - |
| Indian | 0.58 | 0.20, 1.69 | 0.316 | | - | - | - |
| Chinese | 1.37 | 0.72, 2.60 | 0.340 | | - | - | - |
| Malay† | 1 | | | | - | - | |
| **Education level of primary caregiver** | | | 0.949 | 0.001 | | | - |
| None, primary or lower secondary | 0.92 | 0.41, 2.05 | 0.837 | | - | - | - |
| Upper secondary | 1.03 | 0.51, 2.08 | 0.934 | | - | - | - |
| Tertiary† | 1 | | | | - | - | |
| **Income category** | | | 0.303 | 0.017 | | | - |
| Bottom 40% | 1.07 | 0.50, 2.27 | 0.866 | | - | - | - |
| Middle 40% | 0.66 | 0.31, 1.38 | 0.264 | | - | - | - |
| Top 20%† | 1 | | | | - | - | |

Table 4.16, continued

| | Unadjusted OR | 95% CI | p value | Pseudo $R^2$ | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Number of children** | | | 0.462 | 0.011 | | | - |
| 1 - 2 children | 1.16 | 0.51, 2.62 | 0.719 | | - | - | - |
| 3 - 4 children | 1.59 | 0.70, 3.64 | 0.270 | | - | - | - |
| ≥5 children† | 1 | | | | - | - | |
| **Number of disabled child** | | | | | | | |
| Two or more | 1.17 | 0.49, 2.82 | 0.727 | 0.001 | - | - | - |
| One† | 1 | | | | - | - | |
| **Caregiver has medical problem** | | | | | | | |
| Yes | 0.91 | 0.65, 1.28 | 0.185 | 0.012 | 1.69 | 0.81, 3.52 | 0.157 |
| No† | 1 | | | | 1 | | |
| **ABILITIES Index score** | 1.02 | 1.00, 1.03 | 0.088 | 0.018 | 1.00 | 0.98, 1.03 | 0.729 |
| **Number of services needed** | 1.19 | 1.05, 1.33 | **0.005** | 0.056 | 1.22 | 1.03, 1.43 | **0.019** |

†Reference category

In the multivariate model, the pseudo $R^2$ is 0.108 and the no. of respondents = 221

The reference category for complex samples logistic regression was "Received needed services".

### 4.5 Caregiver Needs

Factor analysis of the Caregiver Needs Scale (CNS) revealed four domains (table 4.17): need for Help getting information and services for child (5 items), Help coping with child (6 items), Help getting child care (3 items) and Help with finances (3 items). There were 3 items not grouped into any factor. The reader is advised to refer to Appendix H for more details of the psychometric properties of the CNS.

**Table 4.17:** Items in the Caregiver Needs Scale grouped by domains following factor analysis

| **Help getting information and services for child** | **Help coping with child** | **Help getting child care** | **Help with finances** | **Other items** |
|---|---|---|---|---|
| Information on current services available for child<br><br>Information on future services for child<br><br>Information on how to integrate therapy into daily activities<br><br>Information on child's disability<br><br>Getting care coordination | Learning how to manage stress<br><br>Finding someone to talk to about problems<br><br>Opportunities to talk to other parents of disabled children<br><br>Information on how to play or communicate with child<br><br>Information on how to handle child's behaviour<br><br>Having more time for oneself | Finding trained person for day care<br><br>Finding respite care<br><br>Help with paying for child care | Help with paying for daily expenses<br><br>Help with paying for child's education/ therapy<br><br>Help with paying for special equipment/ toys that child needs | Finding suitable education/ therapy for child<br><br>Finding social or recreational activities for child<br><br>Finding transport to medical appointments |

### 4.5.1 Distribution of caregiver needs

The "Help getting information and services for child" domain had the highest mean score, followed by "Help with finances" and "Help coping with child" (table 4.18 and figure 4.3). The "Help getting child care" domain had the lowest mean score.

**Table 4.18:** Distribution of responses and mean score for items in the Caregiver Needs Scale by domains, weighted by type of disability (n = 305)

| Domains and items | Percentage that definitely need help with this item† (%) | 95% CI | Mean score | 95% CI |
|---|---|---|---|---|
| **Help getting information and services for child** | | | 3.61 | 3.46, 3.77 |
| Information on current services available for child | 57.0 | 50.5, 63.3 | 3.57 | 3.39, 3.74 |
| Information on future services for child | 75.0 | 68.9, 80.3 | 4.08 | 3.92, 4.24 |
| Information on how to integrate therapy into daily activities | 54.3 | 47.8, 60.6 | 3.49 | 3.30, 3.67 |
| Information on child's disability | 53.0 | 46.5, 59.5 | 3.46 | 3.28, 3.64 |
| Getting care coordination | 56.4 | 49.9, 62.7 | 3.52 | 3.32, 3.72 |
| **Help with finances** | | | 3.29 | 3.13, 3.45 |
| Help with paying for daily expenses | 39.5 | 33.4, 46.0 | 3.17 | 2.98, 3.35 |
| Help with paying for child's education/therapy | 55.9 | 49.4, 62.2 | 3.57 | 3.39, 3.75 |
| Help with paying for special equipment/toys | 43.3 | 37.1, 49.7 | 3.12 | 2.92, 3.32 |
| **Help coping with child** | | | 3.11 | 2.97, 3.25 |
| Learning how to manage stress | 38.1 | 32.0, 44.7 | 3.13 | 2.96, 3.31 |
| Finding someone to talk to about problems | 34.1 | 28.2, 40.6 | 2.98 | 2.81, 3.16 |
| Opportunities to talk to other parents | 31.1 | 25.4, 37.4 | 2.94 | 2.77, 3.11 |
| Information on how to play or communicate with child | 44.8 | 38.5, 51.4 | 3.29 | 3.10, 3.47 |
| Information on how to handle child's behaviour | 50.2 | 43.7, 56.6 | 3.45 | 3.28, 3.62 |
| Having more time for oneself | 29.4 | 23.8, 35.8 | 2.79 | 2.62, 2.97 |

Table 4.18, continued

| Domains and items | Percentage that definitely need help with this item[†] (%) | 95% CI | Mean score | 95% CI |
|---|---|---|---|---|
| **Help getting child care** | | | 2.30 | 2.13, 2.47 |
| Finding trained person for daycare | 25.2 | 19.9, 31.3 | 2.37 | 2.17, 2.57 |
| Finding respite care | 18.2 | 13.7, 23.8 | 2.13 | 1.95, 2.32 |
| Help paying for child care | 23.4 | 18.3, 29.5 | 2.37 | 2.17, 2.57 |
| **Other items** | | | | |
| Finding suitable education/ therapy for child | 60.2 | 53.7, 66.3 | 3.63 | 3.44, 3.82 |
| Finding social or recreational activities for child | 47.5 | 41.0, 54.0 | 3.37 | 3.18, 3.56 |
| Finding transport to medical appointments | 18.0 | 13.5, 23.5 | 2.31 | 2.13, 2.50 |

[†] Response 4 and 5 (4 = Help very much needed, 5 = Help extremely needed)

The highest item mean score was for information on future services, followed by help finding suitable education or therapy for the child, information on current services, help paying for education or therapy services and help getting care coordination. The lowest item mean scores were for finding a trained person for day care, help paying for child care, finding transport to medical appointments and finding respite care. When responses were grouped into caregivers that definitely needed help with a particular item (response 4 and 5), the order of items almost totally corresponded to the order of items by mean scores.

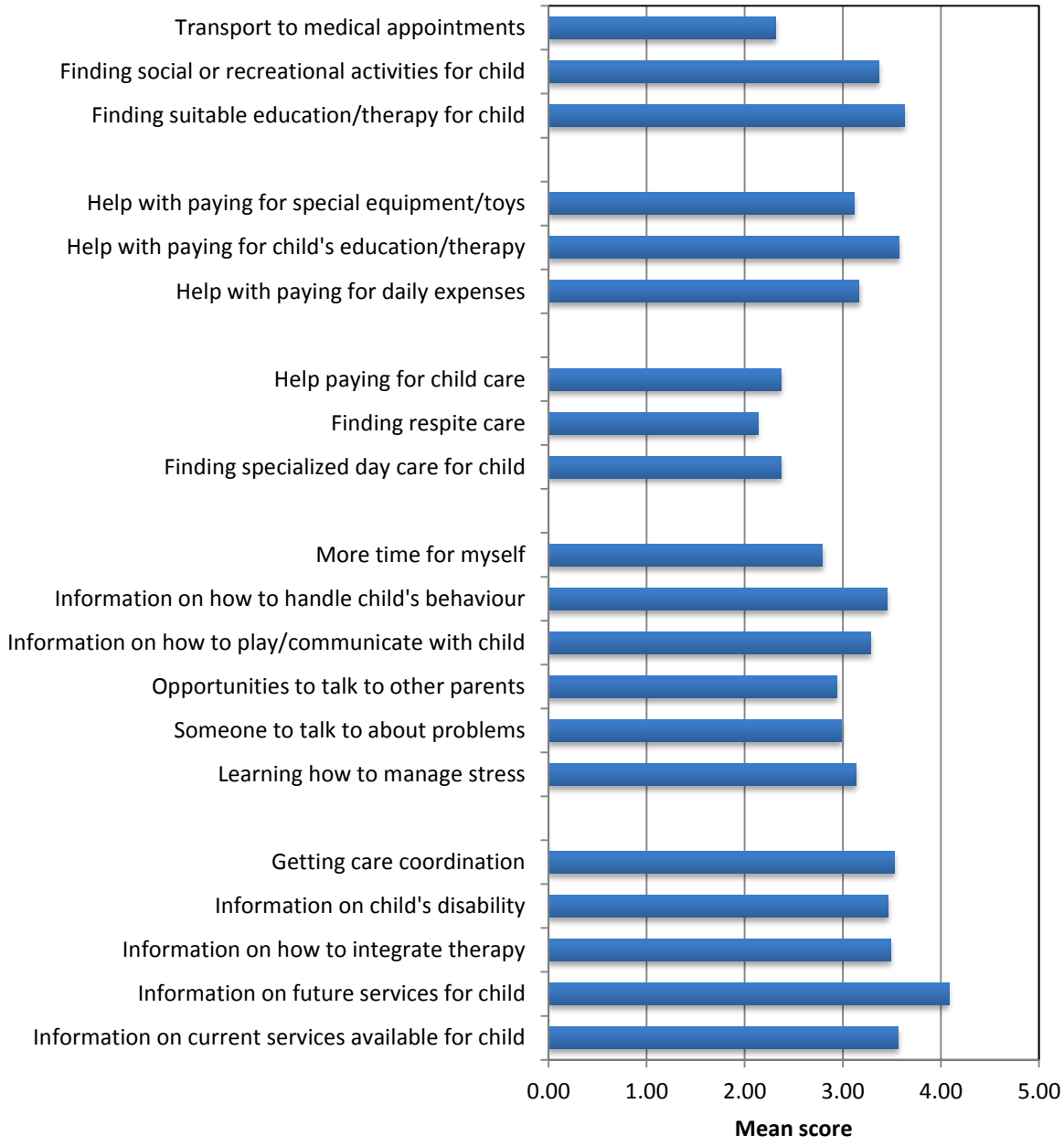


**Figure 4.3:** Mean score for items in the Caregiver Needs Scale

### 4.5.2 Child and family characteristics predisposing to having more caregiver needs

#### 4.5.2.1 Need for help getting information and services for child

Number of children and the presence of a medical problem in either caregiver were not entered as independent variables in this domain because these were not expected to influence the need for help getting information and services for the child. In a separate bivariate analysis, there was no difference in mean caregiver needs score for help getting information and services for child by number of children ($p = 0.781$) and presence of medical problem in either caregiver ($p = 0.934$).

Disability category, age of the child, education level of the primary caregiver, household income level and severity of disability were associated with caregiver needs for getting information and services for child on bivariate analysis (table 4.19). Ethnicity and number of disabled child in the family were not associated with caregiver needs in this domain.

On bivariate analysis, initially caregivers of children with multiple disabilities were found to have more caregiver needs in this domain compared to children with learning disability and other disability. Caregivers with none, primary or lower secondary education reported less caregiver needs than caregivers with upper secondary and tertiary education. Caregivers in the bottom 40% income level also reported less caregiver needs than caregivers in the middle 40% and top 20% income level.

In multivariate analysis, age of the child and severity of disability remained associated with caregiver needs for getting information and services for child. Children aged 0 – 3 and 4 – 6 years had higher caregiver needs subscale score than children aged 7 – 12 years. As parents of younger children are just exposed to the difficulties faced by their child due to disability, they need more information and help getting the services that

their child needs. Higher ABILITIES Index score, which indicates higher severity of disability, is related to higher scores in this domain.

However, on multivariate analysis, caregivers of children with learning disability now reported more information needs compared to children with other disabilities. Caregivers of children with multiple disabilities were no longer found to express more needs. After adjusting for other variables, caregiver's education level and income level no longer predicted caregiver needs in this domain.

**Table 4.19:** Factors associated with Need for Help getting Information and Services for Child

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Disability category** | | | **<0.001** | 0.041 | | | 0.030 |
| Learning | 3.57 | 3.36, 3.78 | 0.128 | | 3.97 | 3.76, 4.18 | **0.016** |
| Multiple | 4.11 | 3.93, 4.29 | <0.001 | | 3.69 | 3.35, 4.02 | 0.647 |
| Others† | 3.33 | 3.12, 3.55 | | | 3.58 | 3.31, 3.86 | |
| **Age** | | | **<0.001** | 0.088 | | | **<0.001** |
| 0 – 3 | 4.09 | 3.77, 4.41 | 0.001 | | 3.97 | 3.61, 4.33 | 0.002 |
| 4 – 6 | 4.21 | 4.05, 4.37 | <0.001 | | 3.95 | 3.72, 4.17 | <0.001 |
| 7 - 12† | 3.42 | 3.23, 3.61 | | | 3.32 | 3.13, 3.52 | |
| **Ethnicity** | | | 0.826 | 0.002 | | | - |
| Indian | 3.59 | 3.14, 4.05 | 0.949 | | - | - | - |
| Chinese | 3.68 | 3.42, 3.95 | 0.540 | | - | - | - |
| Malay† | 3.58 | 3.38, 3.78 | | | - | - | |
| **Education level of primary caregiver** | | | 0.114 | 0.025 | | | 0.488 |
| None, primary or lower secondary | 3.35 | 3.03, 3.67 | 0.092 | | 3.65 | 3.26, 4.04 | 0.785 |
| Upper secondary | 3.73 | 3.54, 3.92 | 0.960 | | 3.86 | 3.65, 4.08 | 0.501 |
| Tertiary† | 3.74 | 3.42, 4.06 | | | 3.73 | 3.40, 4.05 | |

Table 4.19, continued

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Income category** | | | 0.049 | 0.033 | | | 0.333 |
| Bottom 40% | 3.39 | 3.11, 3.66 | **0.034** | | 3.56 | 3.27, 3.85 | 0.163 |
| Middle 40% | 3.79 | 3.56, 4.01 | 0.941 | | 3.77 | 3.54, 4.00 | 0.511 |
| Top 20%† | 3.81 | 3.53, 4.09 | | | 3.91 | 3.54, 4.27 | |
| **No. of disabled child** | | | 0.337 | 0.005 | | | - |
| Two or more | 3.39 | 2.90, 3.88 | | | - | - | |
| One† | 3.64 | 3.48, 3.81 | | | - | - | |
| **ABILITIES Index score**‡ | 0.025 | 0.016, 0.034 | **<0.001** | 0.112 | 0.024 | 0.012, 0.035 | **<0.001** |

†Reference category ‡Parameter estimates presented instead of mean scores

In the multivariate model, the $R^2$ is 0.218 and no. of respondents = 242

In summary, caregivers of children who are not of school going age, children with more severe disability and children with learning disability had more need for help getting information and relevant services for their child.

#### 4.5.2.2 Need for help with finances

Before adjusting for other variables, factors found to be associated with need for help with finances were category of disability, age of the child, ethnicity, education level of primary caregiver, income level, presence of medical problem in a caregiver and severity of disability (table 4.20). Number of children and number of disabled child were not associated with need for help with finances.

In bivariate analysis, caregivers of children with multiple disabilities had more financial needs than children with learning disability and other disability. Indian families had more financial needs compared to Chinese families. Families in the bottom 40% and middle 40% of income level had more financial needs than families in the top 20%.

After adjustment in the multivariate model, category of disability and income level did not remain significant for financial needs. Caregivers of children aged 4 – 6 years had more financial needs compared to caregivers of children aged 7 – 12 years old. Indians had more need for help with finances compared to Malays.

Caregivers who had none, primary or lower secondary education had more financial needs compared to caregivers who had tertiary education. Caregivers who had upper secondary education also had more financial needs than caregivers who had tertiary education. In summary, caregivers who had less than tertiary education had more financial needs.

Presence of medical problem in a caregiver was associated with the family having more financial needs. Need for help with finance was also higher in caregivers of children with more severe disability.

**Table 4.20:** Factors associated with Need for Help with Finances

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Disability category** | | | <0.001 | 0.054 | | | 0.430 |
| Learning | 3.20 | 2.98, 3.41 | 0.436 | | 3.66 | 3.34, 3.99 | 0.233 |
| Multiple | 3.92 | 3.70, 4.14 | **<0.001** | | 3.70 | 3.27, 4.13 | 0.312 |
| Others† | 3.06 | 2.80, 3.33 | | | 3.45 | 3.10, 3.79 | |
| **Age** | | | 0.001 | 0.038 | | | <0.001 |
| 0 – 3 | 3.29 | 2.73, 3.85 | 0.723 | | 3.52 | 2.95, 4.10 | 0.553 |
| 4 – 6 | 3.78 | 3.54, 4.01 | **<0.001** | | 3.95 | 3.63, 4.27 | **<0.001** |
| 7 - 12† | 3.18 | 2.99, 3.38 | | | 3.34 | 3.09, 3.58 | |
| **Ethnicity** | | | 0.174 | 0.009 | | | 0.096 |
| Indian | 3.67 | 3.26, 4.07 | 0.091 | | 3.87 | 3.40, 4.33 | **0.032** |
| Chinese | 3.22 | 2.95, 3.50 | 0.759 | | 3.57 | 3.20, 3.94 | 0.325 |
| Malay† | 3.28 | 3.07, 3.49 | | | 3.37 | 3.12, 3.63 | |
| **Education level of primary caregiver** | | | **0.013** | 0.034 | | | 0.055 |
| None, primary or lower secondary | 3.43 | 3.11, 3.75 | 0.014 | | 3.76 | 3.32, 4.19 | 0.087 |
| Upper secondary | 3.39 | 3.17, 3.62 | 0.008 | | 3.78 | 3.48, 4.09 | **0.017** |
| Tertiary† | 2.90 | 2.62, 3.18 | | | 3.27 | 2.87, 3.67 | |
| **Income category** | | | **0.004** | 0.039 | | | 0.443 |
| Bottom 40% | 3.45 | 3.16, 3.73 | 0.011 | | 3.58 | 3.20, 3.96 | 0.722 |
| Middle 40% | 3.51 | 3.26, 3.75 | 0.002 | | 3.75 | 3.38, 4.11 | 0.242 |
| Top 20%† | 2.95 | 2.69, 3.20 | | | 3.48 | 3.07, 3.89 | |
| **No. of children** | | | 0.889 | 0.001 | | | - |
| 1 - 2 | 3.25 | 3.01, 3.50 | 0.752 | | - | - | - |
| 3 - 4 | 3.21 | 2.96, 3.47 | 0.627 | | - | - | - |
| ≥5† | 3.33 | 2.95, 3.71 | | | - | - | |

Table 4.20, continued

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **No. of disabled child** | | | 0.671 | 0.001 | | | - |
| Two or more | 3.15 | 2.68, 3.63 | | | - | - | |
| One† | 3.26 | 3.10, 3.43 | | | - | - | |
| **Caregiver has medical problem** | | | **0.013** | 0.029 | | | **0.034** |
| Yes | 3.60 | 3.31, 3.90 | | | 3.82 | 3.43, 4.20 | |
| No† | 3.15 | 2.97, 3.34 | | | 3.39 | 3.13, 3.65 | |
| **ABILITIES Index score‡** | 0.023 | 0.014, 0.033 | **<0.001** | 0.082 | 0.018 | 0.006, 0.031 | **0.005** |

†Reference category ‡Parameter estimates presented instead of mean scores

In the multivariate model, the $R^2$ is 0.186 and the no. of respondents = 235.

### 4.5.2.3 Need for help coping with child

Category of disability, age, education level and severity of disability were associated with caregiver needs for help with coping on both bivariate and multivariate analyses (table 4.21). Ethnicity, income level, number of children, number of disabled child, the presence of medical problem in the caregiver, Informal and Formal Family Support scores were not associated with coping needs.

Caregivers of children with learning disabilities had more need for help with coping compared to caregivers of children with multiple disabilities and children with other disabilities. There was no difference in coping needs score between caregivers of children with multiple disabilities and children with other disabilities.

Caregivers of children aged 0 – 3 years and also 4 – 6 years had more need for help with coping and parenting than caregivers of children aged 7 – 12 years. This may be because caregivers whose children are very young are still new to the role of parenting a child with a disability.

Caregivers with none, primary or lower secondary education reported less need for help with coping compared to caregivers with upper secondary education. The mean for the first category does not fall in the 95% confidence interval of the second category and vice versa. There was no difference between caregivers with none, primary or lower secondary education with caregivers who had tertiary education. There was also no difference between caregivers with upper secondary education and caregivers with tertiary education.

Higher severity of disability was associated with more need for help with coping.

**Table 4.21:** Factors associated with Need for Help Coping with Child

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Disability category** | | | **<0.001** | 0.052 | | | **<0.001** |
| Learning | 3.18 | 3.00, 3.37 | <0.001 | | 3.44 | 3.22, 3.66 | <0.001 |
| Multiple | 3.33 | 3.12, 3.55 | <0.001 | | 2.80 | 2.45, 3.15 | 0.692 |
| Others† | 2.55 | 2.31, 2.80 | | | 2.71 | 2.42, 3.00 | |
| **Age** | | | **0.034** | 0.023 | | | **0.015** |
| 0 – 3 | 3.46 | 3.06, 3.85 | 0.048 | | 3.25 | 2.84, 3.66 | 0.013 |
| 4 – 6 | 3.34 | 3.10, 3.59 | 0.036 | | 3.01 | 2.74, 3.27 | 0.038 |
| 7 - 12† | 3.02 | 2.85, 3.19 | | | 2.69 | 2.51, 2.87 | |
| **Ethnicity** | | | 0.920 | 0.001 | | | - |
| Indian | 3.16 | 2.71, 3.62 | 0.765 | | - | - | - |
| Chinese | 3.14 | 2.92, 3.37 | 0.728 | | - | - | - |
| Malay† | 3.09 | 2.90, 3.28 | | | - | - | |

Table 4.21, continued

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Education level of primary caregiver** | | | 0.054 | 0.026 | | | 0.067* |
| None, primary or lower secondary | **2.88** | **2.62, 3.13** | 0.290 | | **2.79** | **2.46, 3.12** | 0.396 |
| Upper secondary | **3.28** | **3.08, 3.48** | 0.277 | | **3.20** | **2.99, 3.41** | 0.134 |
| Tertiary† | 3.08 | 2.80, 3.37 | | | 2.96 | 2.68, 3.24 | |
| **Income category** | | | 0.813 | 0.002 | | | - |
| Bottom 40% | 3.08 | 2.84, 3.32 | 0.565 | | - | - | - |
| Middle 40% | 3.17 | 2.95, 3.39 | 0.915 | | - | - | - |
| Top 20%† | 3.19 | 2.91, 3.46 | | | - | - | |
| **No. of children** | | | 0.889 | 0.001 | | | - |
| 1 - 2 | 3.14 | 2.94, 3.33 | 0.816 | | - | - | - |
| 3 - 4 | 3.06 | 2.84, 3.29 | 0.934 | | - | - | - |
| ≥ 5† | 3.08 | 2.68, 3.49 | | | - | - | |
| **No. of disabled child** | | | 0.597 | 0.001 | | | - |
| Two or more | 3.21 | 2.77, 3.65 | | | - | - | |
| One† | 3.08 | 2.93, 3.23 | | | - | - | |
| **Caregiver has medical problem** | | | 0.217 | 0.007 | | | - |
| Yes | 3.25 | 2.98, 3.52 | | | - | - | |
| No† | 3.05 | 2.89, 3.21 | | | - | - | |
| **ABILITIES Index score‡** | 0.021 | 0.012, 0.029 | **<0.001** | 0.083 | 0.024 | 0.014, 0.035 | **<0.001** |

†Reference category ‡Parameter estimates presented instead of mean scores

* p>0.05 but mean score for none, primary and lower secondary category does not fall in the 95% CI of upper secondary category

In the multivariate model, the $R^2$ is 0.200 and the no. of respondents = 245

#### 4.5.2.4 Need for help getting child care

Category of disability, age of the child, ethnicity, education level of the primary caregiver, income level, number of children in the family and severity of disability were associated with need for help getting child care on bivariate analysis (table 4.22).

Caregivers of children with learning disabilities needed more help getting child care compared to caregivers of children with other disability. Caregivers of children with multiple disabilities also needed more help getting child care compared to caregivers of children with learning disabilities and other disabilities.

Caregivers of children aged 4 – 6 years needed more help getting child care compared to caregivers of children aged 7 – 12 years and children aged 0 – 3 years. But there was no difference in the need for help with child care between caregivers of children aged 0 – 3 years and children aged 7 – 12 years.

Caregivers with tertiary education needed more help getting child care than caregivers with upper secondary education. In addition, caregivers in the top 20% of income level needed more help getting child care compared to caregivers who were in the middle 40% and bottom 40% of income level. Caregivers might not be able to work because they had to take care of their child, but because they are taking care of their child full time, they had less need for help with child care.

Caregivers who had 1 – 2 children had more need for help getting child care compared to caregivers who had 3 – 4 children or ≥5 children. It is possible that the siblings of the child with disability, especially if they are older, might help their parents take care of their disabled sibling. Chinese had more need for help getting child care compared to Malays, but there was no difference between Indians and Malays. Worsening severity of disability was associated with more need for help getting child care.

However, in multivariate analysis, ethnicity, caregiver's education level and income level were no longer associated with need for help getting child care. There were also a few minor changes in the associations between disability category, age of the child and number of children in the family with child care needs.

Caregivers of children with multiple disabilities no longer had more child care needs compared to caregivers of children with learning disability. Caregivers of children aged 4 – 6 years were no longer found to need more help getting child care compared to caregivers of children aged 0 – 3 years. Having 1 – 2 children was no longer associated with more child care needs compared to having 3 – 4 children.

In summary, caregivers of children with learning and multiple disabilities, children of younger age, with more severe disability and caregivers with fewer children needed more help getting child care.

**Table 4.22:** Factors associated with Need for Help getting Child Care

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Disability category** | | | **<0.001** | 0.048 | | | **0.007** |
| Learning | 2.33 | 2.10, 2.57 | <0.001 | | 2.50 | 2.08, 2.93 | 0.002 |
| Multiple | 2.70 | 2.44, 2.97 | <0.001 | | 2.45 | 1.94, 2.97 | 0.065 |
| Others† | 1.71 | 1.50, 1.93 | | | 1.93 | 1.55, 2.31 | |
| **Age** | | | 0.007 | 0.035 | | | 0.019 |
| 0 – 3 | 2.17 | 1.59, 2.74 | 0.925 | | 2.18 | 1.57, 2.79 | 0.713 |
| 4 – 6 | 2.81 | 2.49, 3.13 | **0.002** | | 2.66 | 2.20, 3.11 | **0.005** |
| 7 - 12† | 2.19 | 1.99, 2.40 | | | 2.06 | 1.75, 2.37 | |
| **Ethnicity** | | | 0.021 | 0.037 | | | 0.179 |
| Indian | 2.18 | 1.47, 2.89 | 0.878 | | 2.18 | 1.37, 2.99 | 0.969 |
| Chinese | 2.65 | 2.35, 2.96 | **0.006** | | 2.55 | 2.15, 2.94 | 0.064 |
| Malay† | 2.12 | 1.91, 2.34 | | | 2.16 | 1.91, 2.42 | |

Table 4.22, continued

| | Unadjusted mean score | 95% CI | p value | $R^2$ | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|---|
| **Education level of primary caregiver** | | | 0.060 | 0.026 | | | 0.624 |
| None, primary or lower secondary | 2.35 | 2.01, 2.68 | 0.298 | | 2.39 | 1.92, 2.87 | 0.779 |
| Upper secondary | 2.10 | 1.88, 2.32 | **0.021** | | 2.19 | 1.84, 2.54 | 0.623 |
| Tertiary† | 2.61 | 2.24, 2.99 | | | 2.31 | 1.80, 2.81 | |
| **Income category** | | | 0.122 | 0.020 | | | 0.305 |
| Bottom 40% | **2.20** | **1.90, 2.49** | 0.052 | | 2.11 | 1.69, 2.53 | 0.129 |
| Middle 40% | **2.27** | **1.99, 2.55** | 0.093 | | 2.24 | 1.84, 2.65 | 0.210 |
| Top 20%† | **2.65** | **2.30, 2.99** | | | 2.54 | 2.06, 3.01 | |
| **No. of children** | | | **0.002** | 0.057 | | | 0.084 |
| 1 – 2 | 2.59 | 2.33, 2.85 | 0.001 | | 2.57 | 2.20, 2.93 | **0.026** |
| 3 – 4 | 2.14 | 1.88, 2.39 | 0.143 | | 2.35 | 1.92, 2.78 | 0.124 |
| ≥5† | 1.78 | 1.38, 2.18 | | | 1.97 | 1.48, 2.46 | |
| **No. of disabled child** | | | 0.611 | 0.001 | | | - |
| Two or more | 2.15 | 1.69, 2.60 | | | - | - | |
| One† | 2.27 | 2.09, 2.46 | | | - | - | |
| **Caregiver has medical problem** | | | 0.445 | 0.003 | | | - |
| Yes | 2.40 | 2.04, 2.76 | | | - | - | |
| No† | 2.24 | 2.04, 2.43 | | | - | - | |
| **ABILITIES Index score‡** | 0.020 | 0.010, 0.030 | **< 0.001** | 0.053 | 0.015 | 0.001, 0.028 | **0.036** |

†Reference category ‡Parameter estimates presented instead of mean scores

In the multivariate model, the $R^2$ is 0.216 and no. of respondents = 232.

### 4.6 Access problems to health care services

Overall, difficulties accessing services were mainly due to logistic problems, followed by issues related to skills and resources. Parent-provider relationship problems were least encountered.

The most common reasons for unmet need were that the place of service was too far away, there was no one to go with the child for therapy, caregivers not being able to afford the cost of services/assistive devices and they had no time to ensure their child received needed services/assistive devices because they were busy with other commitments (table 4.23 and figure 4.4).

**Table 4.23:** Distribution of reasons for unmet need

| Reasons for unmet need | Percentage | 95% CI | Unweighted count |
|---|---|---|---|
| **Logistics** | | | |
| Place of service too far | 35.9 | 29.9, 42.4 | 108 |
| No one to go with the child | 32.4 | 26.6, 38.9 | 92 |
| Could not afford cost of services | 32.2 | 26.4, 38.6 | 98 |
| Could not afford cost of assistive devices | 32.2 | 26.6, 38.2 | 116 |
| No time because of other commitments | 32.1 | 26.3, 38.6 | 88 |
| No transport | 19.3 | 14.6, 25.1 | 55 |
| Could not afford cost of transport | 18.5 | 13.9, 24.1 | 55 |
| **Skills and resources** | | | |
| Did not know where to go for service | 31.7 | 25.9, 38.1 | 90 |
| Did not know where to go for devices | 30.5 | 24.9, 36.8 | 97 |
| Appointment date too far | 29.7 | 24.0, 36.0 | 84 |
| Number of sessions inadequate | 25.8 | 20.5, 31.9 | 77 |
| Service provider lack skills | 10.4 | 7.0, 15.1 | 32 |
| Service provider lack equipment | 10.0 | 6.7, 14.6 | 32 |
| **Parent-provider relationship** | | | |
| Poor communication with service provider | 9.8 | 6.6, 14.3 | 33 |
| Previously badly treated | 2.9 | 1.6, 5.0 | 15 |

Caregivers frequently reported not knowing where to go for services or to get assistive devices more than transportation issues and service provider problems. Around 25 – 30% of caregivers reported the appointment date to meet a service provider was too far or that the number of sessions with the service provider was inadequate. Only about 10% of caregivers found service providers to be lacking skills or equipment. Communication problems, which included language barriers, were also only reported in about 10% of caregivers. Less than 5% of caregivers had been previously badly treated by service providers.

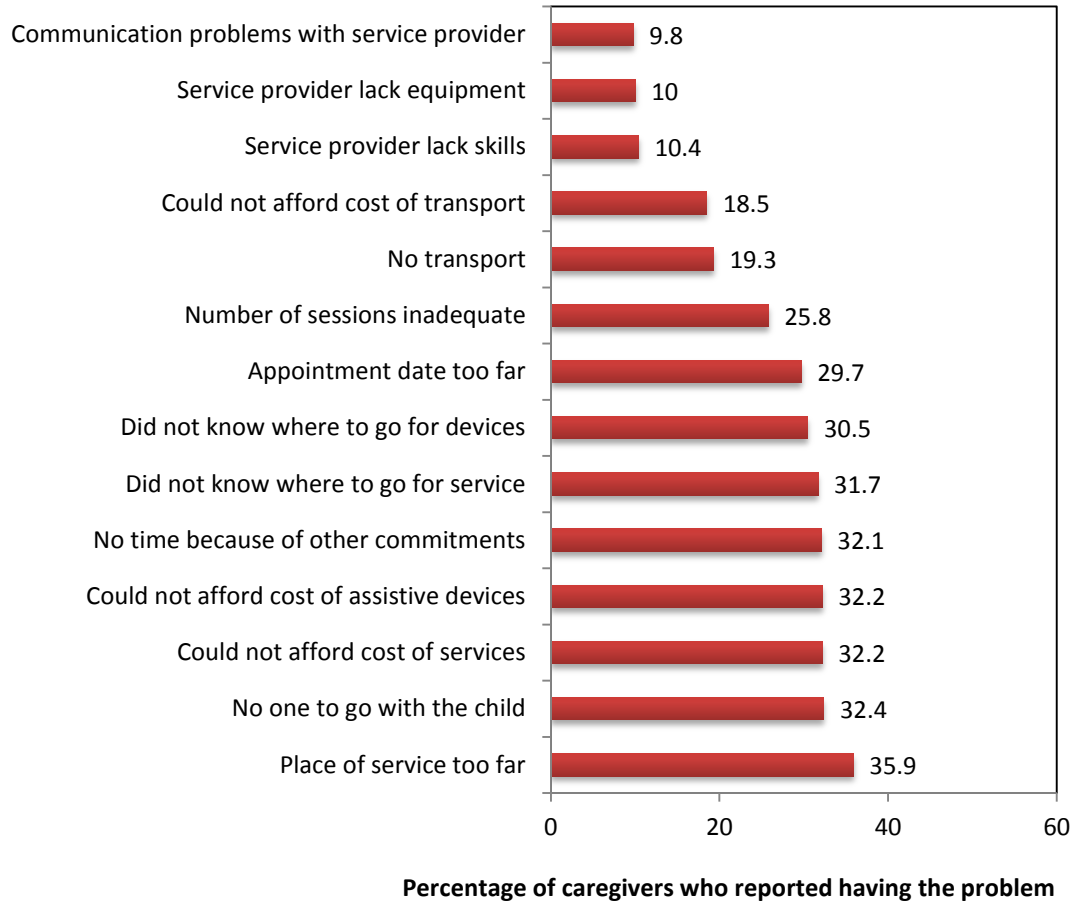


**Figure 4.4:** Distribution of reasons for unmet needs

The most cited reason for unmet need in children with learning disability was that the place of service was too far away, followed by caregivers not having time because of other commitments and no one to go with the child for therapy (table 4.24 and figure 4.5). More than 30% of families also did not know where to go for therapy or could not afford the cost of therapy.

**Table 4.24:** Distribution of reasons for unmet need in children with learning disability and children with multiple disabilities

| | Learning disability | | Multiple disabilities | |
|---|---|---|---|---|
| Reasons for unmet need | % | 95% CI | % | 95% CI |
| **Logistics** | | | | |
| Place of service too far | 36.5 | 28.5, 45.3 | 40.5 | 30.5, 51.4 |
| No one to go with the child | 34.9 | 27.1, 43.7 | 36.9 | 27.2, 47.8 |
| Could not afford cost of services | 32.5 | 24.9, 41.3 | 38.1 | 28.3, 49.0 |
| Could not afford cost of assistive devices | 26.2 | 19.2, 34.7 | 52.4 | 41.6, 62.9 |
| No time because of other commitments | 35.7 | 27.8, 44.5 | 32.1 | 23.0, 42.9 |
| No transport | 20.6 | 14.4, 28.7 | 21.4 | 13.9, 31.6 |
| Could not afford cost of transport | 19.0 | 13.1, 26.9 | 19.0 | 12.0, 29.0 |
| **Skills and resources** | | | | |
| Did not know where to go for service | 34.1 | 26.3, 42.9 | 31.0 | 21.9, 41.7 |
| Did not know where to go for devices | 29.4 | 22.0, 38.0 | 44.0 | 33.8, 54.9 |
| Appointment date too far | 31.7 | 24.2, 40.4 | 31.0 | 21.9, 41.7 |
| Number of sessions inadequate | 26.2 | 19.2, 34.6 | 35.7 | 26.1, 46.6 |
| Service provider lack skills | 10.3 | 6.1, 17.0 | 13.1 | 7.4, 22.2 |
| Service provider lack equipment | 9.5 | 5.5, 16.1 | 15.5 | 9.2, 25.0 |
| **Parent-provider relationship** | | | | |
| Poor communication with service provider | 8.7 | 4.9, 15.1 | 16.7 | 10.1, 26.3 |
| Previously badly treated | 0.8 | 0.1, 5.5 | 8.3 | 4.0, 16.6 |

The most cited reason for unmet need among children with multiple disabilities was that caregivers could not afford the cost of assistive devices, followed by not knowing where to go to obtain those devices. The third most common reason for unmet need was that the place of service was too far away. More than 35% of families also could not afford the cost of services, no one to go with the child for therapy and the number of therapy sessions was inadequate.

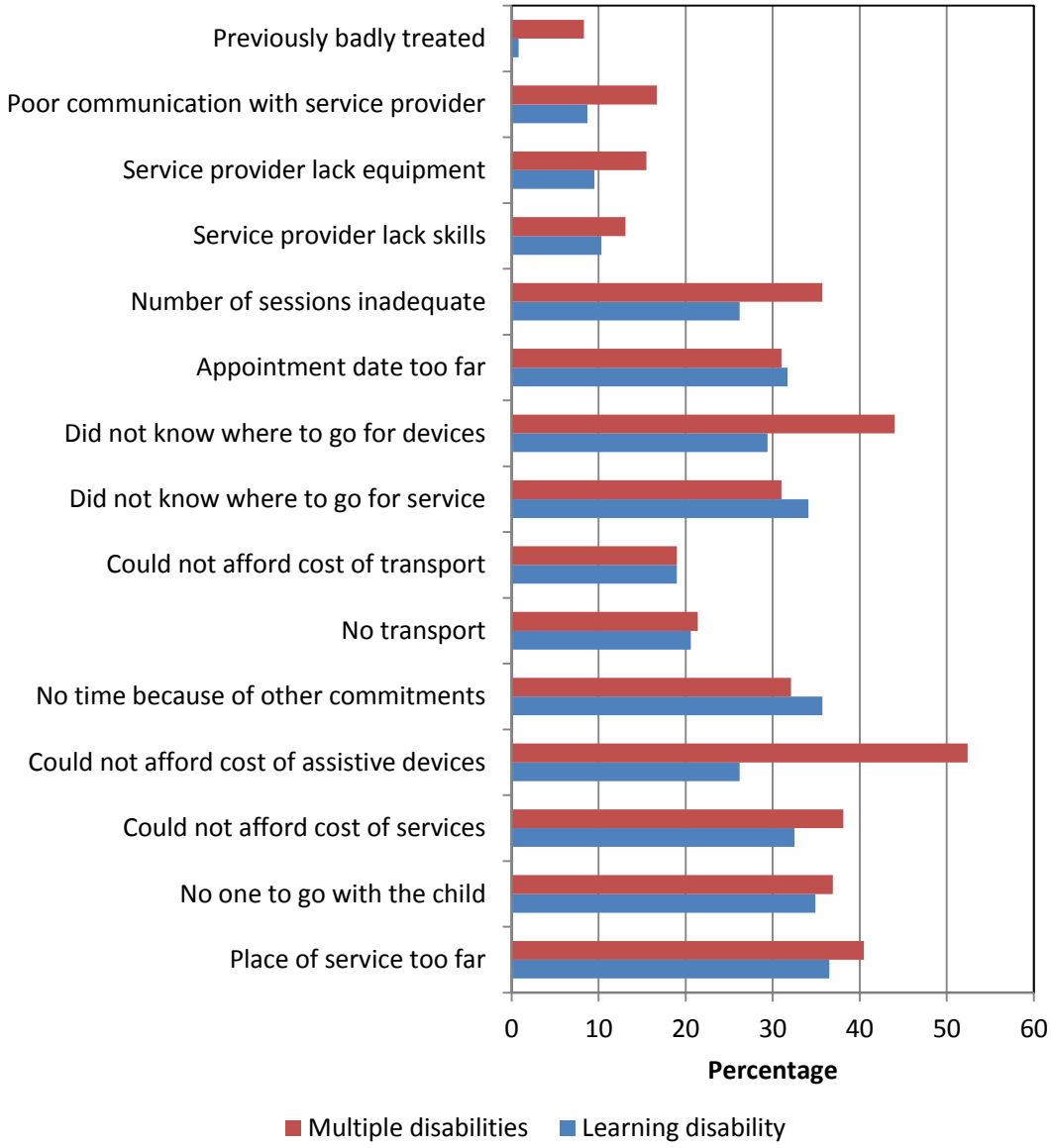


**Figure 4.5:** Distribution of reasons for unmet need in children with learning disability and multiple disabilities

### 4.7 Utilization of rehabilitation services

Rehabilitation services refer to physiotherapy, occupational therapy and early intervention programmes. Caregivers were asked how frequently their children utilized any of these services in the past one year. The objective of studying utilization of rehabilitation services is to see the patterns of utilization in different groups of children with disabilities. Because rehabilitation services here refer to physiotherapy, occupational therapy and Early Intervention Programme (EIP), children with visual and hearing disability are not expected to utilize these services much. Results are focused on children with learning disability and multiple disabilities.

Data is analysed for these two groups of children separately because the pattern of utilization of services for children with learning disability would be different from the pattern of utilization for children with multiple disabilities. Children with learning difficulties in Malaysia are referred for occupational therapy associated with acquisition of learning skills such as improving attention and verbal/non-verbal communication. Children with multiple disabilities would utilize physiotherapy and occupational therapy for difficulties in physical functioning or activities of daily living, even though some may also undergo occupational therapy for learning difficulties.

### 4.7.1 Distribution of utilization of rehabilitation services

It was found that 83.3% (95% CI 73.7, 89.9) of children with multiple disabilities and 56.3% (95% CI 47.5, 64.8) of children with learning disability received rehabilitation services in the past one year (table 4.25).

**Table 4.25:** Receipt of rehabilitation services among children with learning disability and multiple disabilities

| | Learning (n = 126) | | | Multiple (n = 84) | | |
|---|---|---|---|---|---|---|
| **Receive therapy** | % | 95% CI | Unweighted count | % | 95% CI | Unweighted count |
| Yes | 56.3 | 47.5, 64.8 | 71 | 83.3 | 73.7, 89.9 | 70 |
| No | 27.0 | 19.9, 35.5 | 34 | 13.1 | 7.4, 22.2 | 11 |
| Not relevant* | 11.1 | 6.7, 18.0 | 14 | 2.4 | 0.6, 9.1 | 2 |
| Not answered | 5.6 | 2.7, 11.3 | 7 | 1.2 | 0.2, 8.1 | 1 |
| Total | | | 126 | | | 84 |

*Not relevant – children with a disability whom caregivers felt that they do not require therapy in the past one year

Among those who received rehabilitation services, a higher percentage of children with multiple disabilities received them more than once a month and in 2 or more facilities (table 4.26). Approximately three quarters of children with learning disability and also children with multiple disabilities received therapy from government hospital, while one quarter received therapy from government health clinic. A higher percentage of children with multiple disabilities received therapy from community based rehabilitation centres (PDK). The percentage of children who received therapy from the private sector and NGOs were comparable between both groups.

**Table 4.26:** Frequency of therapy, number of facilities and type of facility where children with learning disability and multiple disabilities received rehabilitation services

| | Learning disability | | | Multiple disabilities | | |
|---|---|---|---|---|---|---|
| | % | 95% CI | Unweighted count | % | 95% CI | Unweighted count |
| **Frequency of therapy** | | | | | | |
| Once every 4 - 6 months | 14.1 | 7.7, 24.4 | 10 | 7.1 | 3.0, 16.2 | 5 |
| Once every 2 - 3 months | 9.9 | 4.7, 19.4 | 7 | 4.3 | 1.4, 12.6 | 3 |
| Once a month | 29.6 | 20.0, 41.3 | 21 | 24.3 | 15.6, 35.8 | 17 |
| More than once a month | 46.5 | 35.1, 58.2 | 33 | 64.3 | 52.3, 74.7 | 45 |
| Total | | | 71 | | | 70 |
| **No. of facilities** | | | | | | |
| 1 | 56.3 | 44.6, 67.4 | 40 | 47.1 | 35.7, 58.9 | 33 |
| 2 | 32.4 | 22.5, 44.2 | 23 | 35.7 | 25.3, 47.7 | 25 |
| >2 | 11.3 | 5.7, 21.0 | 8 | 17.1 | 9.9, 27.9 | 12 |
| Total | | | 71 | | | 70 |
| **Type of facility** | | | | | | |
| Hospital | 73.2 | 61.6, 82.3 | 52 | 72.9 | 61.1, 82.1 | 51 |
| Health clinic | 23.9 | 15.3, 35.4 | 17 | 27.1 | 17.9, 38.9 | 19 |
| PDK | 23.9 | 15.3, 35.4 | 17 | 38.6 | 27.8, 50.6 | 27 |
| Private hospital/ therapist | 15.5 | 8.7, 26.0 | 11 | 17.1 | 9.9, 28.0 | 12 |
| NGO centre | 21.1 | 13.1, 32.3 | 15 | 22.9 | 14.4, 34.3 | 16 |

Notes:

a) Percentage was calculated for those who answered they received therapy in the past one year

b) One child could receive therapy from more than one facility

Out of 48 children in the sample who were bedridden, 87.6% (95% CI 74.1, 94.5) received rehabilitation services. Most of them received therapy at a government hospital, followed by a community based rehabilitation centre and NGO centre (Appendix L). Among children who were bedridden, 50.3% (95% CI 36.1, 64.4) received home visits. Out of this, 41.5% ((95% CI 23.3, 57.5) received home visit from a health clinic nurse and 79.1% (95% CI 57.5, 91.4) received it from a community based rehabilitation worker.

In addition, children with learning disability and co-existing behavioural problem utilized rehabilitation services more than those without behavioural problem. A detailed analysis of utilization of rehabilitation services focusing on this group of children is presented in Appendix L.

### 4.7.2 Factors associated with receipt of therapy

Responses for receipt of therapy were available for 105 children with learning disability, whereby 71 received therapy and 34 did not receive therapy. For multiple disabilities, there were 81 responses, 70 received and 11 did not. Because the group sizes were grossly different for multiple disabilities, and since a majority of them received therapy, it was more appropriate to focus on the learning disability group.

Only bivariate analysis was performed for each independent variable. Multivariate analysis was not performed because the small number of respondents did not reach the required minimum sample size.

The district where the family lived, caregiver's education level, income level, severity of disability and informal family support were not associated with receipt of therapy among children with learning disability (table 4.27).

Chinese had lower odds of receiving therapy compared to Malays. When Malays and Indians were grouped together, Chinese still had lower odds of receiving therapy (OR 0.31, 95% CI 0.13, 0.73, p = 0.08). On further examination, it was found that Chinese were less likely to receive therapy for learning disability from government hospital (OR 0.41, 95% CI 0.18, 0.94, p = 0.036) but more likely to receive therapy from NGOs (OR 4.21, 95% CI 1.30, 13.6, p = 0.017). There was no difference in receipt of therapy from private centres.

Among children with learning disability, an increase in formal family support increases the odds of receiving therapy, before adjusting for other variables. The relationship may be bidirectional in that caregivers of children who received therapy might be more likely to report formal support sources to be helpful.

**Table 4.27:** Factors associated with receipt of therapy among children with learning disability from bivariate analysis

| | Crude OR | 95% CI Lower | Upper | p value | Pseudo $R^2$ |
|---|---|---|---|---|---|
| **District** | | | | 0.400 | 0.058 |
| North Seberang Perai | 1.71 | 0.46 | 6.39 | 0.425 | |
| Central Seberang Perai | 0.59 | 0.17 | 2.05 | 0.401 | |
| South Seberang Perai | 1.08 | 0.29 | 4.00 | 0.911 | |
| South West | 2.15 | 0.44 | 10.56 | 0.341 | |
| North East | 1 | | | | |
| **Ethnicity** | | | | 0.029 | 0.096 |
| Indian | 1.19 | 0.12 | 11.82 | 0.881 | |
| Chinese | 0.31 | 0.13 | 0.75 | **0.010** | |
| Malay | 1 | | | | |
| **Education level of primary caregiver** | | | | 0.128 | 0.055 |
| None, primary or lower secondary | 0.38 | 0.12 | 1.18 | 0.093 | |
| Upper secondary | 0.87 | 0.28 | 2.72 | 0.808 | |
| Tertiary | 1 | | | | |
| **Income category** | | | | 0.237 | 0.040 |
| Bottom 40% | 0.50 | 0.17 | 1.43 | 0.196 | |
| Middle 40% | 1.10 | 0.36 | 3.39 | 0.867 | |
| Top 20% | 1 | | | | |
| **ABILITIES Index score** | 1.03 | 0.98 | 1.07 | 0.261 | 0.019 |
| **Informal Family Support Score** | 1.06 | 1.00 | 1.13 | 0.058 | 0.052 |
| **Formal Family Support Score** | 1.22 | 1.09 | 1.36 | **<0.001** | 0.218 |

Note: Reference category for the outcome is “Did not receive therapy”

## 4.8 Financial Impact

### 4.8.1 Income and care expenditure for child with disability

The data on household income and care expenditure in families of children with disabilities has not been weighted, so children with learning disability are underrepresented. Household income and care expenditure were not normally distributed. There were more families with lower income and with lower care expenditure (table 4.28).

**Table 4.28:** Distribution of household income (RM per month) in families of children with disabilities (n = 295)

| **Sources of income** | Minimum | Maximum | Mean | SD | Median |
|---|---|---|---|---|---|
| Income from work | 0.00 | 18000.00 | 2173.49 | 2097.41 | 1500.00 |
| Income from Department of Social Welfare | 0.00 | 1800.00 | 126.03 | 212.39 | 100.00 |
| Income from other sources | 0.00 | 450.00 | 17.56 | 70.62 | 0 |
| Total income | 150.00 | 18150.00 | 2316.52 | 2078.56 | 1650.0 |

RM = Ringgit Malaysia

Overall, the highest mean care expenditures were for child care, transportation and other care expenses, while the lowest mean care expenditures were for prescribed medicine and dental treatment (table 4.29). This was also true for all categories of disability (table 4.30). In addition, the third highest mean care expenditure among children with learning disability was for education, while the second highest mean care expenditure among children with sole vision, hearing, physical or speech disability was for medical devices. Among children with multiple disabilities, the fourth and fifth highest care expenditures were for alternative treatment and ward admission.

**Table 4.29:** Distribution of care expenditure (RM per year) for child with disability (n = 277)

| **Type of expenditure** | Minimum | Maximum | Mean | SD | Median |
|---|---|---|---|---|---|
| Doctor's visit | 0.00 | 9000.00 | 256.66 | 720.84 | 0 |
| Ward admission | 0.00 | 10000.00 | 262.24 | 952.86 | 0 |
| Prescribed medicine | 0.00 | 2400.00 | 83.81 | 289.23 | 0 |
| Complementary medicine | 0.00 | 3600.00 | 268.40 | 555.10 | 0 |
| Medical devices | 0.00 | 8000.00 | 244.68 | 985.85 | 0 |
| Dental treatment | 0.00 | 1680.00 | 25.27 | 135.99 | 0 |
| Other allied health services | 0.00 | 10000.00 | 307.38 | 1091.64 | 0 |
| Transportation | 0.00 | 7200.00 | 528.14 | 903.69 | 240 |
| Child care | 0.00 | 12000.00 | 734.17 | 1745.18 | 0 |
| Alternative treatment | 0.00 | 6000.00 | 217.62 | 702.14 | 0 |
| Education | 0.00 | 6000.00 | 408.79 | 937.12 | 0 |
| Other care expenses | 0.00 | 12000.00 | 1085.28 | 1734.53 | 285 |
| Total | 0.00 | 30780.00 | 4417.32 | 5201.98 | 2885 |

**Table 4.30:** Distribution of care expenditure (RM per year) for child with disability according to category of disability

| Type of expenditure | Learning | | Multiple | | Others | |
|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD |
| Doctor's visit | 259.66 | 608.62 | 190.78 | 375.78 | 314.25 | 1031.31 |
| Ward admission | 193.12 | 766.68 | 332.72 | 1232.71 | 283.22 | 866.59 |
| Prescribed medicine | 71.93 | 273.59 | 78.94 | 270.40 | 103.22 | 325.37 |
| Complementary medicine | 341.14 | 700.99 | 283.73 | 506.14 | 163.00 | 339.63 |
| Medical devices | 23.39 | 137.87 | 230.86 | 899.74 | 534.78 | 1481.49 |
| Dental treatment | 27.25 | 126.40 | 39.26 | 200.24 | 9.77 | 39.50 |
| Other allied health services | 385.92 | 1357.77 | 221.23 | 784.62 | 289.20 | 959.96 |
| Transportation | 517.29 | 1014.26 | 660.69 | 1010.67 | 418.32 | 591.53 |
| Child care | 941.83 | 2159.68 | 830.37 | 1690.21 | 384.41 | 1035.58 |
| Alternative treatment | 185.41 | 699.97 | 391.11 | 953.85 | 96.44 | 275.71 |
| Education | 568.58 | 1207.63 | 278.01 | 714.32 | 330.34 | 676.48 |
| Other care expenses | 612.61 | 937.46 | 2111.57 | 2170.53 | 721.98 | 1661.49 |
| Total | 4128.13 | 4952.08 | 5649.27 | 5451.39 | 3641.56 | 5124.75 |

Overall, 45.8% of families spent <10% of their income, 22.2% spent 10 – 19.99% of their income, and 32.0% spent ≥20% on care expenditure for their child with disability (table 4.31). Approximately half of the families of children with learning disability and other disability spent <10% of their income on care expenditure, but a slightly higher percentage of families of children with other disabilities spent ≥20% of their income on care expenditure. It has been shown earlier that families of children with other disabilities spent more on medical devices, for example vision, hearing and physical aids, which could explain the higher expenditure as a percentage of income.

It was found that 46.9% of children with multiple disabilities spent ≥20% of their income on care expenditure, compared to 24.3% of children with learning disability and 27.6% of children with other disabilities. Children with multiple disabilities have more need for services and assistive devices, which explains their higher care expenditure.

**Table 4.31:** Distribution of income spent on care expenditure

| Disability category | Percentage of income spent on care expenditure | | | | | | |
|---|---|---|---|---|---|---|---|
| | <10% | | 10 – 19.99% | | ≥20% | | |
| | Percentage | No. | Percentage | No. | Percentage | No. | Total no. |
| Overall | 45.8 | 126 | 22.2 | 61 | 32.0 | 88 | 275 |
| Learning | 52.3 | 56 | 23.4 | 25 | 24.3 | 26 | 107 |
| Multiple | 27.2 | 22 | 25.9 | 21 | 46.9 | 38 | 81 |
| Others | 55.2 | 48 | 17.2 | 15 | 27.6 | 24 | 87 |

Expenditure would also depend on severity of disability, age of the child, and whether the child is bedridden. Spearman correlation was tested between total expenditure, ABILITIES Index score and age of the child. Total expenditure was found to be correlated with ABILITIES Index score ( $r = 0.329$, $p = 0.01$ ) and age of the child ( $r = -0.300$, $p = 0.01$). Higher severity of disability and younger age of the child was

associated with higher care expenditure. Total expenditure was also higher for children who were bedridden (p = 0.008).

### 4.8.2 Financial impact on families of children with disabilities

Financial impact on families of children with disabilities was investigated by finding out whether the care expenditure for the child had caused financial and employment problems to the family. For this analysis, data was weighted by type of disability.

Among the caregivers, 35.2% (95% CI 29.3, 41.5) reported having a big financial problem while 53.1% (95% CI 46.6, 59.4) reported having problems with work as a result of caring for a child with disability (table 4.32). Employment problem was defined as caregivers having to stop work or took too many days off from work.

**Table 4.32:** Prevalence of financial problem and employment problem in families of children with disabilities

| | Percentage | 95% CI Lower | Upper | Unweighted count |
|---|---|---|---|---|
| **Financial problem** | | | | |
| No problem | 12.9 | 9.0 | 18.2 | 33 |
| Small problem | 44.4 | 38.0 | 51.0 | 133 |
| Big problem | 35.2 | 29.3 | 41.5 | 117 |
| Not answered | 7.5 | 4.6 | 11.8 | 22 |
| **Employment problem** | | | | |
| Yes | 53.1 | 46.6 | 59.4 | 176 |
| No | 45.0 | 38.7 | 51.5 | 122 |
| Not answered | 1.9 | 0.8 | 4.6 | 7 |

About a third of caregivers (either parent) had to leave their job to take care of their child and 40.6% (95% CI 34.5, 47.0) took too many leave days to attend to their child's needs. Among the caregivers, 20.3% (95% CI 15.6, 26.1) had a big problem getting permission to take time off from work to attend to their child (table 4.33).

**Table 4.33:** Types of employment problem among families of children with disabilities

| | Estimate percentage | 95% CI Lower | Upper | Unweighted count |
|---|---|---|---|---|
| Caregiver had to stop work | 31.4 | 25.8 | 37.6 | 105 |
| Taking too many leave days | 40.6 | 34.5 | 47.0 | 134 |
| Problem getting permission for time off work | 62.7 | 56.2 | 68.8 | 189 |
| Small problem | 42.4 | 36.1 | 48.9 | 128 |
| Big problem | 20.3 | 15.6 | 26.1 | 61 |

Note: Caregivers could report more than one type of employment problem

Between the three groups, caregivers of children with multiple disabilities had the highest percentage of having a big financial problem, having to leave their job, taking too many leave days and facing a big problem getting permission to take time off work to attend to their child's needs (table 4.34).

**Table 4.34:** Distribution of financial and employment problems by disability category

| | Learning | | Multiple | | Others | |
|---|---|---|---|---|---|---|
| | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count |
| **Financial problem** | | | | | | |
| Small problem | 45.2 (36.7, 54.1) | 57 | 36.9 (27.2, 47.8) | 31 | 47.7 (37.7, 57.8) | 45 |
| Big problem | 31.7 (24.2, 40.4) | 40 | 53.6 (42.8, 64.0) | 45 | 33.5 (24.6, 43.7) | 32 |
| **Employment problem** | | | | | | |
| Had to stop work | 27.8 (20.6, 36.3) | 35 | 51.2 (40.5, 61.8) | 43 | 29.2 (20.8, 39.2) | 27 |
| Taking too many leave days | 36.5 (28.5, 45.3) | 46 | 57.1 (46.3, 67.4) | 48 | 43.4 (33.9, 53.4) | 40 |
| Problem getting time off work | 63.5 (54.7, 71.5) | 80 | 65.5 (54.6, 74.9) | 55 | 56.7 (46.2, 66.6) | 54 |
| Small problem | 42.9 (34.4, 51.7) | 54 | 39.3 (29.4, 50.2) | 33 | 43.1 (33.2, 53.3) | 41 |
| Big problem | 20.6 (14.4, 28.7) | 26 | 26.2 (17.8, 36.7) | 22 | 13.6 (7.9, 22.3) | 13 |

Note: Caregivers could report more than one type of employment problem

### 4.8.3 Factors associated with having financial problem and employment problem

Families who spent a higher percentage of their income on their child's care expenditure were more likely to have a big financial problem. Compared to families who spent <10% of their income on care expenditure, families who spent ≥20% of their income had higher odds of having financial problem (OR 10.1, 95% CI 4.71, 21.68, p <0.001). Families who spent 10 – 19.99% of their income on care expenditure also had higher odds of having financial problem (OR 2.96, 95% CI 1.36, 6.46, p = 0.007). The higher the percentage of income spent on care expenditure, the higher the odds of having financial problem.

Analysis was done to find out whether families of children with disabilities who had more service needs and who may require more help with their care (such as children who were bedridden) experienced more financial and employment problems. Other factors which may indirectly cause the family to have more or less financial problem such as number of children and caregiver having a medical problem were also included.

In bivariate analysis, families of children with multiple disabilities, children who were bedridden, with more severe disability and who reported more service needs had higher odds of having a financial problem (table 4.35). Indians compared to Malays, having none, primary or lower secondary education vs tertiary education, income level in the bottom 40% vs top 20% and presence of medical problem in a caregiver were also associated with having financial problem.

Because type and severity of disability were closely related to whether the child was bedridden and to the number of service needs, the latter two variables were not entered into the multivariate model. Younger age of the child, Indians, and caregiver having medical problems remained associated with financial problem, after adjusting for type and severity of disability, education and income level.

**Table 4.35:** Factors associated with having financial problem

| | Unadjusted OR | 95% CI | p value | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Disability category** | | | 0.007 | | | 0.437 |
| Learning | 0.92 | 0.51, 1.65 | 0.780 | 1.38 | 0.67, 2.83 | 0.386 |
| Multiple | 2.25 | 1.20, 4.20 | **0.011** | 2.02 | 0.64, 6.30 | 0.227 |
| Others | 1 | | | 1 | | |
| | | | | | | |
| **Age** | | | 0.059 | | | **0.011** |
| 0 – 3 | 2.37 | 0.94, 5.95 | 0.067 | 4.19 | 1.43, 12.25 | 0.009 |
| 4 – 6 | 1.90 | 0.96, 3.76 | 0.065 | 2.83 | 1.18, 6.78 | 0.020 |
| 7 – 12 | 1 | | | 1 | | |
| | | | | | | |
| **Ethnicity** | | | 0.054 | | | 0.017 |
| Indian | 4.03 | 1.29, 12.61 | **0.017** | 6.06 | 1.64, 22.32 | **0.007** |
| Chinese | 1.29 | 0.69, 2.40 | 0.424 | 2.17 | 0.90, 5.22 | 0.083 |
| Malay† | 1 | | | 1 | | |
| | | | | | | |
| **Education level of primary caregiver** | | | 0.108 | | | 0.408 |
| None, primary or lower secondary | 2.43 | 1.05, 5.61 | **0.037** | 1.76 | 0.47, 6.62 | 0.401 |
| Upper secondary | 1.92 | 0.90, 4.12 | 0.093 | 2.04 | 0.71, 5.85 | 0.186 |
| Tertiary† | 1 | | | 1 | | |
| | | | | | | |
| **Income category** | | | 0.080 | | | 0.756 |
| Bottom 40% | 2.54 | 1.13, 5.74 | **0.025** | 1.35 | 0.36, 5.12 | 0.656 |
| Middle 40% | 1.98 | 0.87, 4.50 | 0.103 | 1.54 | 0.47, 5.09 | 0.476 |
| Top 20%† | 1 | | | 1 | | |
| | | | | | | |
| **No. of children** | | | 0.386 | | | - |
| 1 - 2 children | 0.69 | 0.31, 1.54 | 0.363 | - | - | - |
| 3 - 4 children | 0.57 | 0.25, 1.27 | 0.168 | - | - | - |
| ≥5 children | 1 | | | - | - | |
| | | | | | | |
| **No. of disabled child** | | | 0.340 | | | - |
| Two or more | 0.65 | 0.27, 1.58 | | - | - | |
| One | 1 | | | - | - | |
| | | | | | | |
| **Caregiver has medical problem** | | | **0.042** | | | **0.018** |
| Yes | 1.88 | 1.02, 3.47 | | 2.52 | 1.17, 5.41 | |
| No | 1 | | | 1 | | |
| | | | | | | |
| **ABILITIES Index score** | 1.02 | 1.00, 1.04 | **0.015** | 1.01 | 0.98, 1.04 | 0.486 |

Table 4.35, continued

| | Unadjusted OR | 95% CI | p value | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Child bedridden** | | | **0.040** | | | - |
| Yes | 1.98 | 1.03, 3.80 | | - | - | |
| No | 1 | | | - | - | |
| **Number of needs** | 1.14 | 1.04, 1.27 | **0.009** | - | - | - |

Reference category for the outcome is "small or no financial problem".
In the multivariate model, the pseudo$R^2$ is 0.183 and the no of respondents = 235

In bivariate analysis, families of children with multiple disabilities, who were bedridden, with more severe disability and who reported more service needs had higher odds of having an employment problem (table 4.36). Families with disabled children aged 0 – 3 years vs 7 – 12 years, Indians, families with 1 – 2 children vs ≥5 children and families with more than one disabled child were also associated with having employment problems.

Disability category, age, ethnicity, number of children, number of disabled child, presence of medical problems in a caregiver and ABILITIES Index score were entered into the multivariate model. Age 0 – 3 years compared to 7 – 12 years, Indians, having 1 – 2 children compared to ≥5 children and having more than one disabled child remained associated with having employment problems. It is difficult to explain the association between having fewer children with the higher odds of having an employment problem. However, the p value for 1 – 2 children vs ≥5 children is very near to 0.05 and the lower border of the 95% CI for the adjusted OR barely misses 1.0, so number of children is not an important predictor of having employment problems.

**Table 4.36:** Factors associated with having employment problem

| | Unadjusted OR | 95% CI | p value | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Disability category** | | | <0.001 | | | 0.667 |
| Learning | 0.67 | 0.39, 1.15 | 0.145 | 0.99 | 0.50, 1.96 | 0.982 |
| Multiple | 2.41 | 1.25, 4.65 | **0.009** | 1.52 | 0.54, 4.31 | 0.430 |
| Others | 1 | | | | 1 | |
| | | | | | | |
| **Age** | | | 0.039 | | | 0.015 |
| 0 – 3 | 2.89 | 1.15, 7.28 | **0.025** | 4.83 | 1.58, 14.73 | **0.006** |
| 4 – 6 | 1.72 | 0.87, 3.41 | 0.120 | 1.93 | 0.82, 4.58 | 0.134 |
| 7 - 12 | 1 | | | | 1 | |
| | | | | | | |
| **Ethnicity** | | | 0.038 | | | 0.083 |
| Indian | 4.85 | 1.43, 16.43 | **0.011** | 4.95 | 1.22, 20.18 | **0.026** |
| Chinese | 1.00 | 0.56, 1.81 | 0.993 | 1.20 | 0.56, 2.54 | 0.637 |
| Malay[†] | 1 | | | | 1 | |
| | | | | | | |
| **Education level of primary caregiver** | | | 0.693 | | | - |
| None, primary or lower secondary | 0.77 | 0.37, 1.62 | 0.492 | - | - | - |
| Upper secondary | 0.99 | 0.50, 1.97 | 0.975 | - | - | - |
| Tertiary[†] | 1 | | | - | - | |
| | | | | | | |
| **Income category** | | | 0.369 | | | |
| Bottom 40% | 1.13 | 0.55, 2.33 | 0.736 | - | - | - |
| Middle 40% | 1.61 | 0.77, 3.34 | 0.204 | - | - | - |
| Top 20%[†] | 1 | | | - | - | |
| | | | | | | |
| **No. of children** | | | 0.123 | | | 0.107 |
| 1 - 2 children | 2.28 | 1.04, 5.03 | **0.041** | 2.69 | 1.02, 7.11 | **0.046** |
| 3 - 4 children | 1.82 | 0.83, 4.00 | 0.133 | 2.46 | 0.97, 6.22 | 0.057 |
| ≥5 children | 1 | | | | 1 | |
| | | | | | | |
| **No. of disabled child** | | | **0.010** | | | **0.009** |
| Two or more | 1.08 | 0.81, 1.43 | | 3.62 | 1.38, 9.49 | |
| One | 1 | | | | 1 | |
| | | | | | | |
| **Caregiver has medical problem** | | | 0.140 | | | 0.131 |
| Two or more | 1.59 | 0.86, 2.93 | | 1.76 | 0.84, 3.65 | |
| One | 1 | | | | | |
| | | | | | | |
| **ABILITIES Index score** | 1.03 | 1.01, 1.05 | **0.004** | 1.02 | 1.00, 1.05 | 0.101 |

Table 4.36, continued

| | Unadjusted OR | 95% CI | p value | Adjusted OR | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Child bedridden** | | | **0.017** | | | - |
| Yes | 2.36 | 1.17, 4.78 | | - | - | |
| No | 1 | | | - | - | |
| **Number of needs** | 1.33 | 1.19, 1.49 | **<0.001** | - | - | - |

Reference category for the outcome is not having employment problem.
In the multivariate model, the pseudo$R^2$ is 0.212 and the no of respondents = 244

## 4.9 Family Support

### 4.9.1 Type and number of supports available to families of children with disabilities

Out of the caregivers, 52.5% (95% CI 45.9, 58.9) had someone to help them with the day to day care of the child (table 4.37). Among the 48 children who were bedridden, 30 or 62.5% (95 % CI 47.5, 75.5) of their caregivers had someone to help.

Most of the help was from the child's grandparents, followed by siblings, other relatives and babysitter. Less than 10% of families had a domestic helper to help with the care of the child. Majority of families had only one person helping and did not join any support group or organization related to the child's disability. The most frequent reason given for not joining any support group or organization was that caregivers did not know of any, followed by they did not have time to join. 11.2% (95% CI 7.4, 16.6) felt there was no such need.

**Table 4.37:** Distribution of types and number of supports available to families of children with disabilities

| | Percentage | 95% CI Lower | Upper | Unweighted count |
|---|---|---|---|---|
| **Someone to help with day to day care of child** | | | | |
| Yes | 52.5 | 45.9 | 58.9 | 160 |
| No | 45.7 | 39.3 | 52.2 | 141 |
| Not answered | 1.8 | 0.6 | 5.1 | 4 |
| Total | | | | 305 |
| **Person helping with day to day care (n = 160)** | | | | |
| Child's siblings | 32.4 | 24.5 | 41.4 | 51 |
| Child's grandparents | 51.6 | 42.6 | 60.5 | 82 |
| Other relatives | 15.7 | 10.3 | 23.1 | 28 |
| Domestic helper | 3.4 | 1.3 | 8.5 | 6 |
| Babysitter | 12.3 | 7.4 | 19.6 | 20 |
| Others | 1.6 | 0.6 | 3.7 | 5 |
| **No. of persons helping with day to day care (n = 160)** | | | | |
| 1 | 84.1 | 76.6 | 89.5 | 131 |
| ≥2 | 15.9 | 10.5 | 23.4 | 29 |
| **Joined any support group/organization related to child's disability** | | | | |
| Yes | 13.0 | 9.3 | 17.9 | 43 |
| No | 83.9 | 78.5 | 88.1 | 255 |
| Not answered | 3.1 | 1.4 | 6.7 | 7 |
| Total | | | | 305 |
| **Reasons for not joining** | | | | |
| No need | 11.2 | 7.4 | 16.6 | 28 |
| No time to join | 22.0 | 16.5 | 28.6 | 52 |
| Do not know of any organization | 46.3 | 39.2 | 53.4 | 120 |
| Do not think it will benefit child | 0.2 | 0 | 1.5 | 1 |
| Others | 4.1 | 2.1 | 8.0 | 11 |
| Not answered | 22.0 | 16.6 | 28.6 | 53 |

Note: Respondents may give more than one reason for not joining any support group/ organization

### 4.9.2 Helpfulness of family support sources

A modified Family Support Scale was used to assess the helpfulness of informal and formal sources of support to families of children with disabilities in the past 6 months. Family Support Scale score was found to approximate a normal distribution, with a skewness of 0.349. The Family Support Scale score had a mean of 25.72 (95% CI 24.07, 27.36). The mean Informal Family Support Score was 16.91 (95% CI 15.82, 17.99) and the mean Formal Family Support Score was 8.79 (95% CI 8.04, 9.55).

Based on the mean family support score and estimated percentages of helpfulness ratings, all the sources of support are generally not very helpful except for the caregiver's spouse (table 4.38). Staff from the child's school, community based rehabilitation centre (PDK) or day care centre, other children in the family, maternal grandparents and health care workers are considered sometimes helpful. Friends, colleagues, other parents of disabled children and NGO staff had the lowest scores. It is possible that help from NGOs was not required by many families, which could have contributed to the low score.

For informal sources of support, a higher percentage of caregivers rated their spouse, other children, and the child's maternal and paternal grandparents as more helpful (table 4.38). For formal sources of support, a higher percentage rated school/PDK or day care centre staff and health care workers as more helpful. Among the respondents, 20.8% (95% CI 15.9, 26.7) rated staff from the Department of Education and 28.5% (95% CI 23.0, 34.7%) rated staff from the Department of Social Welfare as more helpful.

**Table 4.38:** Helpfulness of family support sources based on Family Support Scale score

| Sources of support | % rated as more helpful† | 95% CI | Unweighted count | Mean score | 95% CI |
|---|---|---|---|---|---|
| **Informal support** | | | | | |
| Paternal grandparents | 30.6 | 24.9, 36.9 | 96 | 1.82 | 1.59, 2.05 |
| Maternal grandparents | 34.5 | 28.7, 40.9 | 110 | 2.24 | 2.00, 2.47 |
| Paternal relatives | 18.7 | 14.1, 24.3 | 58 | 1.62 | 1.45, 1.78 |
| Maternal relatives | 22.7 | 17.7, 28.6 | 70 | 1.82 | 1.63, 2.01 |
| Spouse | 67.2 | 60.8, 73.1 | 208 | **3.56** | 3.33, 3.78 |
| Friends | 14.6 | 10.6, 19.8 | 46 | 1.37 | 1.21, 1.53 |
| Other children | 44.6 | 38.2, 51.2 | 132 | 2.30 | 2.06, 2.54 |
| Colleagues | 12.2 | 8.5, 17.2 | 36 | 1.09 | 0.92, 1.26 |
| Parents of other disabled children | 9.0 | 6.0, 13.5 | 29 | 1.04 | 0.89, 1.19 |
| **Formal support** | | | | | |
| Health care workers | 38.1 | 32.1, 44.6 | 123 | 2.19 | 1.97, 2.42 |
| School/PDK/Day care centre | 47.4 | 40.9, 53.9 | 139 | 2.52 | 2.28, 2.76 |
| Department of Social Welfare | 28.5 | 23.0, 34.7 | 89 | 1.79 | 1.58, 2.01 |
| Department of Education | 20.8 | 15.9, 26.7 | 59 | 1.41 | 1.20, 1.61 |
| NGOs | 9.9 | 6.7, 14.4 | 33 | 0.91 | 0.75, 1.07 |

†Score 3 – 5 (generally helpful to extremely helpful)

### 4.9.3 Factors associated with helpfulness of informal and formal family support

Analysis was undertaken to find out whether children with disabilities who had more service needs and who may require more help with their care (such as children who were bedridden or who had behaviour and social skills problem) received more family support. Socio-demographic factors such as ethnicity, education level and income level were also examined to see which group of families with disabled children had more

support. Because type and severity of disability were closely related to whether the child was bedridden and to the number of service needs, the latter two variables were not entered into the multivariate model.

In both bivariate and multivariate analysis, older children had lower informal family support mean scores (table 4.39). Indians and Chinese had lower scores compared to Malays. Having 1 – 2 children in the family was associated with lower scores compared to having 3 – 4 children or ≥5 children. From the 95% CIs of the ORs, families with bottom 40% of income level had lower informal FSS compared to families with top 20% income level, but the p value was not significant.

There was no difference in scores by disability category, education level of the primary caregiver and number of disabled children. Families with children who were bedridden, who had behaviour or social skills problem, higher severity of the disability and higher number of service needs did not receive more informal family support either.

**Table 4.39:** Factors associated with Informal Family Support Mean Score

| | Unadjusted mean score | 95% CI | p value | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Disability category** | | | 0.652 | | | - |
| Learning | 1.84 | 1.68, 2.01 | 0.405 | - | - | - |
| Multiple | 1.93 | 1.76, 2.11 | 0.880 | - | - | - |
| Others† | 1.95 | 1.75, 2.15 | | - | - | |
| **Age** | | | **<0.001** | | | **<0.001** |
| 0 – 3 | 2.66 | 2.20, 3.12 | <0.001 | 2.53 | 2.11, 2.94 | <0.001 |
| 4 – 6 | 2.13 | 1.91, 2.35 | 0.001 | 2.04 | 1.78, 2.31 | 0.008 |
| 7 - 12† | 1.72 | 1.59, 1.85 | | 1.68 | 1.52, 1.83 | |
| **Ethnicity** | | | **<0.001** | | | **0.003** |
| Indian | 1.59 | 1.24, 1.93 | 0.011 | 1.92 | 1.53, 2.31 | 0.029 |
| Chinese | 1.55 | 1.36, 1.74 | <0.001 | 1.96 | 1.71, 2.21 | 0.002 |
| Malay† | 2.08 | 1.93, 2.24 | | 2.37 | 2.18, 2.56 | |

Table 4.39, continued

| | Unadjusted mean score | 95% CI | p value | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Education level of primary caregiver** | | | 0.156 | | | 0.756 |
| None, primary or lower secondary | 1.72 | 1.54, 1.90 | 0.098 | 2.14 | 1.85, 2.42 | 0.777 |
| Upper secondary | 1.91 | 1.74, 2.08 | 0.585 | 2.04 | 1.81, 2.27 | 0.857 |
| Tertiary† | 2.01 | 1.71, 2.30 | | 2.07 | 1.73, 2.41 | |
| **Income category** | | | 0.115 | | | 0.169 |
| Bottom 40% | **1.74** | **1.57, 1.91** | 0.054 | **1.93** | **1.65, 2.21** | 0.062 |
| Middle 40% | 1.93 | 1.72, 2.15 | 0.532 | 2.00 | 1.76, 2.25 | 0.104 |
| Top 20%† | **2.04** | **1.78, 2.29** | | **2.31** | **2.00, 2.62** | |
| **No. of children** | | | 0.073 | | | 0.060 |
| 1 - 2 children | **1.73** | **1.54, 1.92** | 0.033 | **1.88** | **1.66, 2.10** | 0.044 |
| 3 - 4 children | **1.96** | **1.77, 2.16** | 0.544 | **2.18** | **1.92, 2.44** | 0.983 |
| ≥5 children† | **2.06** | **1.82, 2.29** | | **2.18** | **1.91, 2.46** | |
| **No. of disabled children** | | | | | | |
| Two or more | 1.73 | 1.49, 1.98 | 0.228 | - | - | - |
| One† | 1.90 | 1.77, 2.04 | | - | - | - |
| **Child bedridden** | | | | | | |
| Yes | 2.05 | 1.82, 2.29 | 0.146 | - | - | - |
| No† | 1.86 | 1.73, 1.99 | | - | - | |
| **Child has behaviour or social skills problem** | | | | | | |
| Yes | 1.83 | 1.65, 2.01 | 0.470 | - | - | - |
| No† | 1.92 | 1.74, 2.09 | | - | - | |
| **ABILITIES Index score‡** | -0.004 | -0.010, 0.003 | 0.268 | - | - | - |
| **Number of needs‡** | 0.036 | -0.001, 0.073 | 0.059 | - | - | - |

†Reference category ‡Parameter estimates presented instead of mean scores

In the multivariate model, the $R^2$ is 0.202 and the no. of respondents = 262

Indians and Chinese had lower formal family support score compared to Malays, even after adjusting for income level (table 4.40). Families in the bottom 40% and middle 40% income level had lower scores compared to families in the top 20%.

Disability category, caregiver's education level, number of children in the family and number of disabled children were not associated with formal FSS. Families with a child who was bedridden, with a behaviour or social skills problem and higher severity of disability also did not receive more formal family support.

In bivariate analysis, families of children who had more service needs had higher formal family support score. If number of needs was entered into the multivariate model, this association did not remain.

**Table 4.40:** Factors associated with Formal Family Support Mean Score

| | Unadjusted mean score | 95% CI | p value | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Disability category** | | | 0.705 | | | - |
| Learning | 1.77 | 1.56, 1.98 | 0.808 | - | - | - |
| Multiple | 1.87 | 1.63, 2.11 | 0.418 | - | - | - |
| Others† | 1.73 | 1.49, 1.97 | | - | - | |
| **Age** | | | 0.299 | | | - |
| 0 – 3 | 1.88 | 1.29, 2.46 | 0.617 | - | - | - |
| 4 – 6 | 1.98 | 1.70, 2.26 | 0.125 | - | - | - |
| 7 - 12† | 1.72 | 1.54, 1.90 | | - | - | |
| **Ethnicity** | | | **<0.001** | | | **<0.001** |
| Indian | 1.40 | 0.98, 1.81 | 0.002 | 1.51 | 1.09, 1.94 | 0.005 |
| Chinese | 1.26 | 1.03, 1.50 | <0.001 | 1.29 | 1.05, 1.54 | <0.001 |
| Malay† | 2.11 | 1.92, 2.30 | | 2.18 | 2.00, 2.37 | |
| **Education level of primary caregiver** | | | 0.638 | | | - |
| None, primary or lower secondary | 1.75 | 1.45, 2.05 | 0.469 | - | - | - |
| Upper secondary | 1.73 | 1.53, 1.92 | 0.347 | - | - | - |
| Tertiary† | 1.92 | 1.57, 2.27 | | - | - | |

Table 4.40, continued

| | Unadjusted mean score | 95% CI | p value | Adjusted mean score | 95% CI | p value |
|---|---|---|---|---|---|---|
| **Income category** | | | 0.084 | | | **0.004** |
| Bottom 40% | 1.61 | 1.38, 1.85 | **0.029** | 1.41 | 1.16, 1.65 | 0.001 |
| Middle 40% | 1.84 | 1.58, 2.09 | 0.299 | 1.58 | 1.32, 1.85 | 0.023 |
| Top 20%† | 2.06 | 1.73, 2.38 | | 2.00 | 1.72, 2.28 | |
| **No. of children** | | | 0.747 | | | - |
| 1 - 2 children | 1.76 | 1.55, 1.98 | 0.448 | - | - | - |
| 3 - 4 children | 1.79 | 1.53, 2.05 | 0.551 | - | - | - |
| ≥5 children† | 1.93 | 1.56, 2.29 | | - | - | |
| **No. of disabled children** | | | | | | |
| Two or more | 1.62 | 1.26, 1.99 | 0.317 | - | - | - |
| One† | 1.83 | 1.66, 1.99 | | - | - | |
| **Child bedridden** | | | | | | |
| Yes | 1.98 | 1.65, 2.30 | 0.246 | - | - | - |
| No† | 1.76 | 1.60, 1.93 | | - | - | |
| **Child has behaviour or social skills problem** | | | | | | |
| Yes | 1.78 | 1.55, 2.00 | 0.904 | - | - | - |
| No† | 1.76 | 1.53, 1.99 | | - | - | |
| **ABILITIES Index score**‡ | -0.001 | -0.010, 0.009 | 0.904 | - | - | - |
| **Number of needs**‡ | 0.055 | 0.006, 0.105 | **0.029** | - | - | - |

†Reference category ‡Parameter estimates presented instead of mean scores

In the multivariate model, the $R^2$ is 0.160 and the no. of respondents = 267

## 4.10 Conclusion of chapter four

The results showed that 76.5% of children had one or more unmet health care service needs. The services/assistive devices most unmet were dietary advice, psychology services, dental services, communication aids and home modifications. Children with multiple disabilities, of younger age, with more severe disability and caregivers with higher education reported more needs. However, school age children were more likely to have higher level of unmet needs and having more than one disabled child was associated with less unmet needs. Overall, difficulties accessing services were mainly due to logistic problems, followed by issues related to skills and resources.

Caregivers needed the most help getting information and services for their child, followed by help with finances. Caregivers of younger children and with more severe disability had more needs in all domains. In addition, caregivers of children with learning disability needed more help getting information and help with coping. Caregivers of Indian ethnicity, who had less than a tertiary education and who themselves had medical problems needed more help with finances.

Caregiver's education level, income level and severity of disability were not associated with receipt of therapy among children with learning disability. Among the caregivers, 35.2% (95% CI 29.3, 41.5) reported having financial problems while 53.1% (95% CI 46.6, 59.4) reported having employment problems. Caregiver's spouse, other children in the family, the child's grandparents, school, PDK or day care centre staff and health care workers were found to be more helpful sources of family support.

# CHAPTER 5: DISCUSSION

## 5.1 Introduction

This chapter discusses the findings of the study, beginning with the health care service needs of children with disabilities and the magnitude of their unmet needs compared to other studies. The similarities and differences in predisposing characteristics to health care service needs and unmet needs with other studies are discussed after that. This is followed by a discussion on the caregiver needs found in this study and the child and family characteristics associated with having more caregiver needs. Access problems reported in this study, findings on utilization of rehabilitation services, financial impact on the family and helpfulness of family supports are discussed mainly within the local context. The chapter ends with strengths and limitations of the study.

Referring back to the Behavioural Model of Health Services Use, the three constructs in the model are Predisposing Characteristics, Enabling Resources and Needs. Needs in this study on children with disabilities are defined as the child's need for health care services and caregiver needs. Unmet health care service needs occur when there is a mismatch between services that are needed and services that are received.

Predisposing Characteristics in this study are the child and family characteristics associated with needs and unmet needs. Beliefs on disability, such as the presence of stigma and awareness on disability rights, are also in this construct, but were not within the scope of this study. Enabling Resources are service characteristics (identified through access problems) and family supports which promote access. This study examined the social supports available to families through the Family Support Scale.

Barriers to care are grouped into socio-demographics, beliefs about disability and treatment, and service characteristics affecting access to care. Socio-demographics have been covered under Predisposing Characteristics, while beliefs on disability and treatment were not examined in this study. Service characteristics are one of the components under the Enabling Resources construct. Service characteristics relating to skills and resources, logistics and parent-provider relationship were asked as reasons for unmet needs. Questions incorporated the availability and accessibility of services, including knowledge on where to obtain services, cost and distance problems and communication problems with service providers.

### 5.2 Child's health care service needs and unmet needs

Prevalence of unmet need for services depends on the availability and accessibility of those services in the local health system. In this study, prevalence of children who had unmet needs for health care services was higher than that found in developed countries, but lower compared to low and middle income countries. Access problems identified in this study are discussed later in the chapter, keeping in mind that comparability at the international level is limited by the use of different definitions, populations under study and measurement methods.

Unmet need for each service was generally >30%. In comparison, Warfield and Gulley (2006) found that unmet need for each service ranged from 3% for specialty physician services to 12% for mental health services. Differences in findings could be due to cultural variations of perceived needs and differences in access to services between countries. Nevertheless, unmet need for specialist doctor was the least unmet and unmet need for psychology services was the second most unmet, similar to Warfield and Gulley (2006).

Local comparisons could only be made for dental and specialist doctor services. The unmet need for dental services was 59.9% (95% CI 50.8, 68.4), which was similar to the finding by Suriati et al. (2011), which found that 60.4% of caregivers needed help locating a dentist who will see their child. In this study, the unmet need for a specialist doctor was only 37.8% (95% CI 30.6, 45.7), whereas a much higher proportion of respondents needed help locating a doctor who understands their child's need in the other study (59.7%). Children with disabilities are usually referred to a specialist doctor for diagnosis and further management, so it is expected that the need for a specialist doctor would not be high. However, whether the doctor understands the child's need was not explored further in this study.

Dental and nutrition problems are highly prevalent among children with disabilities, as shown in this study, but they are easily detected and respond to treatments that are readily available (Goddard et al., 2008). Children with disabilities often have poor oral health (Hennequin et al., 2008; Norwood Jr & Slayton, 2013), with greater needs and unmet needs for dental services (Lewis, 2002; Hennequin et al., 2008). Medical professionals often did not integrate oral health issues in the health care of children with disabilities, viewing it as a responsibility of parents or dentists (Hallberg & Klingberg, 2005). Good collaboration between medical and dental care is therefore essential.

More awareness about oral health in children with disabilities should be given to health care providers for early dental referral and intervention. Assessment of the child's functioning level could assist in triaging children who need urgent dental examination (Desai et al., 2001). Following examination, diagnosis and treatment planning by a dentist, much of the preventive, simple treatment and oral health promotion could be performed by trained dental assistants.

There is quite a high unmet need for vision related services and vision aids in both children with visual disability and those without (refer Table K10 in Appendix K). Not only do children with visual disability need vision related services and vision aids, but children with other disabilities also can have vision problems, such as short-sightedness, astigmatism and strabismus. The needs for visual assessment and visual aids such as spectacles in children with disabilities other than visual disability need to be addressed.

Home nursing services were needed by only 2.6% (95% CI 1.3, 5.2) of children. The unmet need for home nursing care had a wide confidence interval due to the small number reporting a need and unmet need for this service. Out of 11 children who needed home nursing, 6 did not have this need met. It would be desirable to find out what exactly is the home nursing care needed and whether the care can be provided by a community nurse or paediatric nurse.

Community nurses in Malaysia are not specially paediatric trained and paediatric trained nurses are mostly hospital based. Home nursing services for children who are medical technology-dependent are best provided by trained paediatric nurses and not general community nurses, due to the specialist nature of the services (McIntosh & Runciman, 2008). If a paediatric nurse is required, then the person who plays the role of the care coordinator can perhaps liase with the hospital for paediatric nurses to conduct home visits until the caregiver is confident of handling the medical technology.

Caregivers may not need long term help with nursing care at home, but home nursing services can be helpful for children with chronic special care needs after an episode of hospitalization for an acute medical event. Certain changes to the type of care the child needs may have occurred, such as initiation of nasogastric tube feeding, requiring the caregiver to undergo a period of adaptation which would benefit from some home nursing help.

This study found high needs for speech therapy, occupational therapy and communication aids; an understandable finding since children with learning difficulties make up a majority of children with disabilities.

Many children with disabilities in this study have communication problems, requiring the services of speech therapists and the use of communication aids. However, these needs were more frequently unmet than the needs for mobility, vision and hearing related services or aids. Others have reported the same findings. Dusing et al. (2004) found that the prevalence of unmet needs for communication aids was higher than for vision aids or mobility aids. Even among children with speech and hearing difficulties, Kenney and Kogan (2011) found that unmet need for communication aids was higher than unmet need for hearing aids. Reasons for this could be the technical challenges of prescribing communication aids and lower priority assigned to communication compared to other impairments (Lindsay, 2010).

Compared to mobility problems, communication problems such as speech delay tend to be overlooked in the early years of a child's development. Caregivers and service providers alike may assume that the child can catch up with his peers later. Speech delay is actually a warning sign that the child will have problems with learning later on in life. The importance of this finding is currently not being emphasized enough to parents and to health care workers involved in assessing early childhood development, leading to a lack of proper early assessment and intervention of communication problems.

Communication is important for interaction with others, expressing self, and establishing self-determination and independence. Children who have communication problems may experience limitations in participation in activities of daily living and social activities with family members. There is a need for more interventions that

enhance communication skills. Speech therapists can help explore options for using communication devices for children with limited speech and communication abilities, and special educators may contribute by adapting the classroom environment to promote language development.

There is a lack of proper early assessment and intervention of communication problems in Malaysia, with the lack of speech therapists and audiologists being mentioned as requiring urgent attention (NIH, 2006a). Alternative and Augmentative Communication Aids (AAC) should be made more available by overcoming problems of lack of awareness, lack of training and cost.

There was a high prevalence of unmet need for psychological services in this study, similar to the finding by (Warfield & Gulley, 2006). High unmet need for psychological or mental health services among children with intellectual disabilities and challenging behaviour have been found in other studies (Beecham et al., 2002; Douma et al., 2006), leaving parents and teachers with little support on how to cope with challenging behaviour. Physical health needs were usually met but needs relating to behaviour problems were rarely met (Beecham et al., 2002). Mental health was one of the most neglected areas of service delivery for people with intellectual disabilities in Australia (Goddard et al., 2008). The poor development of mental health services has been attributed to lack of recognition at the primary care level and insufficient numbers of trained mental health professionals (McCarthy & Boyd, 2002).

As more children with pervasive developmental disorders such as autism are diagnosed, the demand for this service will continue to increase. Service providers are encouraged to implement interventions that promote development of effective adaptive behaviours among children with disabilities, preferably with child psychologists taking the lead. There is a lack of clinical child psychologists in Malaysia at the moment, meaning that

doctors and occupational therapists have to fill the gap in this expertise. Thus, they have to learn how to assess developmental/behavioural problems and prescribe interventions to address these problems.

Caregivers' expression of service needs for their child correlated with their child's impairment, except for need for psychological services. Only about one third of caregivers of children with behavioural or social skills problem felt their child needed psychological services. Parents may feel that the child's problem is unchangeable, may not be aware that they can seek professional help for the problem, or there could still be a stigma attached to seeking psychological services.

In comparison, about three quarters of caregivers of children with communication problems felt their child needed speech therapy and around 90% of caregivers of children with visual disability and hearing disability reported their child needed vision related and hearing related services respectively.

In the absence of a clear impairment indicator, the need for physiotherapy was analysed for children with physical disability and multiple disabilities. However, type of physical impairment does not directly relate to the need for physiotherapy services. Impairments in limb functioning may not necessarily benefit from physiotherapy if the impairment is due to a structural anomaly. Usually it is children with increased or reduced muscle tone who need physiotherapy. Mobility problems have been used to indicate a child's need for contact with physiotherapists (Beecham et al., 2002) but reduced mobility due to structural anomaly may be better served by mobility aids rather than physiotherapy.

An important issue is whether children with particular impairments received specific services that were likely to reduce the impact of the impairment on their functioning and participation. A majority of children with behavioural or social skills problem whom their caregivers perceived needed psychological services did not have this need met.

In addition, unmet need for speech therapy among children with communication problems was higher than unmet need for physiotherapy among children with physical and multiple disabilities, unmet need for vision related services among children with visual disability and unmet need for hearing related services among children with hearing disability. The above findings emphasize the need for more psychological and speech therapy services for children who can benefit from them.

The need and receipt of services in primary care and emergency care were not investigated in this study. This study focused on specialist care and therapies. In other studies, lack of access appeared to be less of an issue for medical care (including primary care, emergency care and specialist care) compared to non-medical care and therapies (Porterfield & McBride, 2007; Schmidt et al., 2007).

The current study did not set out to make a distinction on the needs and unmet needs between preventive and therapeutic health care. Preventive health care consists of physical, visual, hearing and dental examinations, growth and development monitoring, health education and immunizations. Children with disabilities should get preventive health care as much as any other child without a disability, but preventive and therapeutic health services for them often overlap. Service providers such as doctors, dentists, nurses and nutritionists play a role in both therapeutic and preventive health care. This study looked at types of services by service provider and did not distinguish whether those services were therapeutic or preventive. Unmet preventive medical care needs were minimal among children with disabilities attending a children's hospital in Germany (Thyen et al., 2003).

### 5.3 Child and family characteristics predisposing to having more health care service needs and unmet needs

Children with multiple disabilities had significantly more needs, but they did not have significantly more unmet needs. This study shows that there is a tendency for children with learning disabilities to have higher level of unmet needs compared to children with other disability, even though the results were statistically not significant. Descriptively, a bigger proportion of children with learning disability were categorized as having high level of unmet needs while a bigger proportion of children with multiple disabilities and other disabilities were categorized as having low or moderate level of unmet needs.

Children with learning disability consistently showed higher percentages of unmet need for specialist doctor services, dental services, dietary/nutritional advice and psychological services than children in the other two groups (refer Appendix K). In addition, children with learning disability also showed higher percentages of unmet need for occupational therapy compared to children with physical disability and multiple disabilities, as well as higher unmet need for speech therapy and communication aids compared to children with hearing or speech disability.

Other studies have likewise identified children who have intellectual impairments or behavioural problems to have more unmet needs than other children with disabilities. Saloojee et al. (2007) found that children with intellectual impairments were more likely not to receive therapy that they needed compared to children with motor impairments whereas Zuckerman, Lindly, Bethell and Kuhlthau (2014) found that children with autistic spectrum disorder were more likely to face difficulties in receiving services than children with other functional limitations.

The difficulties faced by children with intellectual or behavioural problems may be overlooked or misunderstood because their disability is not "visible". Furthermore, it is particularly challenging to treat and communicate with these children. Families of autistic children in Beijing received significantly less economic assistance than families of physically disabled children (Xiong et al., 2011). It is possible that caregivers of children with multiple disabilities actually find it easier to ask for and receive services that they need in view of their child's obvious condition.

Caregivers whose child's disability was more severe reported more needs, even after controlling for type of disability. This finding was consistent with other studies (Warfield & Gulley, 2006; Porterfield & McBride, 2007).

On the other hand, there have been inconsistent findings on the association between severity of disability and unmet needs or access to services. This study did not find an association between severity of disability and unmet needs.

Most studies found that there were more unmet needs when the disability was more severe (Lewis, 2002; van Dyck et al., 2004; Warfield & Gulley, 2006; Baillargeon et al., 2011), yet others found no association (O'Neil et al., 2009). Children with more severe disability have even been found to be *less* likely to have an unmet need (Mayer et al., 2004). In the latter case, the authors discussed the possibility that there is a threshold at which parents become adept at navigating the healthcare system or may have accepted the child's condition as unchangeable and feel they do not need services.

Age is a predictive factor of needs and unmet needs, even after controlling for type of disability. Other studies have shown that younger children had more needs (Warfield & Gulley, 2006; Porterfield & McBride, 2007). In this study, younger children had more needs than school aged children. When the child is young, parents are just starting to recognize the difficulties the child face, and may express more needs to prepare the

child for school and for wider community participation. An older child may have received some of the services when they were younger (such as dental services, hearing assessment, visual assessment) and so these services might be deemed to be no longer necessary.

However, children of school age had higher level of unmet needs, and both pre-school and school aged children were more likely not to receive all needed services compared to the youngest children. These findings are consistent with other studies, where there is an increased risk of access problems to rehabilitation services (O'Neil et al., 2009) and higher perceived environmental barriers (Kertoy et al., 2012) in older children. Parents of children with intellectual disabilities reported insufficient speech therapy as their child got older (Carroll, 2010).

Ethnic minorities faced barriers in accessing health services due to language barriers with service providers (Inkelas et al., 2007), but they were also more likely to be disadvantaged in terms of education and income (Yu et al., 2004). On the other hand, there are studies where child's race or minority status was not a predictor of access problems to rehabilitation or preventive health care services (O'Neil et al., 2009; Tsai et al., 2012). The current study showed that ethnicity did not affect the level of unmet needs.

In this study, having two or more children with disability was associated with less unmet needs compared to having only one child with disability. This is similar to the finding by O'Neil et al. (2009), where having siblings with special health care needs is a protective factor against risk of access problems. The study finding suggests that parents may learn to navigate the health system more effectively when they have had more experience in obtaining services for their other children. Using the analogy from a study on another vulnerable group, people who were homeless longer were more likely

to get care for their medical conditions than the newly homeless (Gelberg, Andersen & Leake, 2000). This was because the former group is more likely to have greater knowledge and awareness of available services for the homeless, as well as methods to travel to locations offering these services.

Consistent with findings from Porterfield and McBride (2007), caregivers with lower education level reported less needs. Caregivers with higher education may be better informed about health issues related to their child and may have more awareness about the rights of the disabled. They may also have greater expectations of their child compared to caregivers with lower education, leading them to report more services needed.

In this study, caregivers' education level did not impact on the level of unmet needs. The association between parental education level and unmet needs varies, with some studies finding lower education associated with more unmet needs, others finding higher education associated with more unmet needs and some finding no association, depending on the type of service needs studied (Mayer et al., 2004; Warfield & Gulley, 2006; Porterfield & McBride, 2007). Parental education level was not a predictor of access problems to rehabilitation services in children with special health care needs in the study by O'Neil et al. (2009).

Initially it was expected that caregivers of lower education level would have more unmet needs because they did not know how to go about getting services that they need. On the other hand, caregivers with higher education may have better insight about services that should be available but are not, and higher expectations on the usefulness of services. In summary, education influences awareness of need for services but had less impact on actual access to services, depending on service characteristics which affect accessibility.

Porterfield and McBride (2007) found that parents with low income were less likely to indicate that their child needed specialist physician or needed prescription medication, but more likely to indicate their need for therapy services. There was no association between income level and reported service needs in the current study. The initial finding that children from families of lower income reported less service needs did not remain significant after adjustment for other variables, most notably education level.

Being poor per se does not influence awareness on the need for services, but can affect the ease of acquiring services. Access to services not only depends on whether families know where to get the services that they need, but also whether they can afford to pay for certain services and assistive devices. Besides that, families of lower income may be more concerned with making a living, and have less time and money to spend on their disabled child. Poverty level and insurance status were reported to be associated with unmet needs in the US NSCSHCN. Families who were poorer or without insurance were more likely to have an unmet need (Dusing et al., 2004; van Dyck et al., 2004; Warfield & Gulley, 2006; Porterfield & McBride, 2007).

Income level did not predict level of unmet needs in this study. Children in this study mainly went to government or publicly funded health care facilities, where services for the disabled are free. The Malaysian public health care sector is financed by general taxation. In the US, health care services are paid for by health insurance. This could explain the differences in findings between income level and unmet needs. Besides that, it is not income level per se which causes problems with access to needed services, but rather the family's ability to pay. The ability to pay is a function of the child's care expenditure relative to the family's income and also after deducting other essential expenses.

Another study in the US did not find family income to be a predictor of access problems, but the risk of having access problems increases when families reported more financial hardship caused by child's health condition and higher out-of-pocket expenses to pay for child's health needs (O'Neil et al., 2009).

Number of children in the family was not associated with level of unmet needs. When parents have more children, they also have to attend to the daily needs of their other children, leaving them with less time and energy to focus on their disabled child. On the other hand, having more children could mean having extra help around the house, with older siblings taking care of younger ones. This could translate into parents having more time to attend to the child with disability.

Children of caregivers who had medical problems were not more likely to have unmet needs than children of caregivers without medical problems. O'Neil et al. (2009) also found that parent's health status did not predict having access problems, but Krauss et al. (2003) found that children whose parents were in poor health were at greater risk of access problems.

There is a concern that if the child needs a lot of services, caregivers may not be able to seek out all the services needed due to financial and time constraints. In this study, having more service needs did not result in more of those services being unmet. Warfield and Gulley (2006) found that children with higher number of service needs had higher prevalence of not receiving one or more of these services. The authors defined unmet need as going without a needed service altogether, whereas in this study, a service partially received was also considered an unmet need. An analysis which grouped needs into those which were not received at all, and those which were received either partially or fully, revealed that higher number of needs was associated with more services not being received.

The second analysis is more objective as caregivers just need to respond yes or no to the question of whether their child received services. However, in reality, services may be lacking in quantity or quality, thus giving rise to the feeling that services were only partially received and needs were not fully met. This researcher prefers to use the first analysis approach as level of unmet needs can be seen as a continuum.

## 5.4 Caregiver needs

Only the trends of family or caregiver needs can be compared to other studies, and not actual scores, because of the use of different response scales.

### 5.4.1 Distribution of caregiver needs

Information on services for the child was the most needed by caregivers in our study, indicating that disability services were either unavailable and/or there was lack of information sharing between service providers and caregivers on where to seek services. Most research has also shown that information needs are the most frequently reported by caregivers (Bailey Jr & Simeonsson, 1988; Perrin et al., 2000; Farmer et al., 2004; Suriati et al., 2011; Siebes et al., 2012; Ueda et al., 2013). Service providers did not provide families with enough information about available services to address their concerns and were perceived to lack the knowledge about available resources (Betz et al., 2004).

In contrast, Thyen et al. (2003) found that relatively few parents of disabled children attending a children's hospital in Germany reported unmet needs for health education or information. Less than a third of parents reported unmet needs for health education or information, whereas in this study, more than two thirds reported needing more help getting information on the child's condition and services for the child.

Different operational definitions might account for some of the differences in the reporting of needs. Thyen et al asked about receipt of service needs while in this study, respondents were asked to rate their need for help, but not their receipt of help. On discussing why results of their findings was different from other studies, Thyen et al mentioned that the emphasis in the questions were different (for example, wanting more information vs assessing whether provision was sufficient).

Need for financial help was rated higher than need for help with coping and help getting child care, although the difference in mean scores was considerably higher in children with multiple disabilities and other disability compared to children with learning disability. Children with multiple disabilities and other disability (visual, hearing, physical) are expected to require assistive technology which incurs extra cost.

In a Malaysian study, Suriati et al. (2011) found that items in the construct 'need for social support' were rated higher than most of the items in the construct 'need for financial help'. A study on children with intellectual disabilities and co-existing behavioural or emotional problems by Douma et al. (2006) also showed that parents needed "a friendly ear/someone to talk to" and "counselling on how to better handle their child's problems" more than need for material help. Differences in population of children with disabilities studied and the instruments used (e.g. Family Needs Survey vs Caregiver Needs Scale) could account for the differences in findings.

However, Park et al. (2009) reported that most support received by Vietnamese mothers was related to material and practical help, rather than emotional support, although it is unclear whether this is due to the unavailability of emotional support services or due to Vietnamese mothers perceiving less need for help with emotional support. Internalizing behaviours such as turning to religion, accepting the fact that their child has a disability, developing a positive outlook and taking action on removing stressors, were coping

strategies more prevalent among Malaysian mothers of children with Down syndrome (Norizan & Khadijah, 2010). Seeking assistance or advice on what to do and getting emotional support from others were less frequently used. Items on need for help with coping in the Caregiver Needs Scale were associated with externalizing behaviours, which might explain why caregivers did not report needing them as much.

In this study, although caregivers rated the construct of financial needs higher than the construct of coping needs, the ratings for individual items varied. "Need for help paying for daily expenses" and "need for help paying for special equipment/toys" in the CNS were rated higher than "finding someone to talk to" but rated lower than "information on how to play or communicate with child" and "information on how to handle child's behaviour".

In regards to emotional support, need for someone to talk to was reported by 60.5% of caregivers in this study. In the study by Suriati et al. (2011), the proportion of caregivers who endorsed the need for someone to talk to was 69.1% for friends, 63.2% for family members, 56% for counsellors and 45.1% for religious person. This study did not make the distinction on whether caregivers preferred getting emotional support from formal or informal sources. Another finding is that 54.9% of respondents in this study wanted more time for themselves, while 45.5% of caregivers in the other study reported this need.

More than half (59.9%) of caregivers in our study indicated a need for help in the item "opportunities to talk to other parents of disabled children", while 74% of respondents in the study by Suriati et al. (2011) reported this need. Support from parents of children with similar health conditions is appreciated as these parents are perceived to face similar challenges and share common experiences.

Formal respite care services are more established in Western than Asian cultures. Respite care is in fact documented as a legal right for families of children with disabilities in countries like Sweden, UK, Australia and New Zealand (DLS, 2009; AIHW, 2014). It was initially expected that caregivers would report a higher need for respite care services in this study, but help 'finding child care when parents need to get away' was low on the list of caregiver needs. It appears that caregivers may be hesitant about leaving their caregiving responsibilities to other people, or that they already had adequate child care support.

For children who have high support needs, including feeding difficulties or behavioural problems, parents may perceive an inability to leave the child with anyone else for fear of a medical emergency. Parents might feel hesitant about leaving their child with someone who does not have the expertise necessary to take care of their child, so this study asked about caregivers' need for help finding trained personnel for child care. The relatively low expression of this need suggests that Malaysian families rely more on informal sources of child care. Help finding and paying for child care services was generally low in both this study and in the study by Suriati et al. (2011).

### 5.4.2 Child and family characteristics predisposing to having more caregiver needs

Both caregivers of children with learning disabilities and multiple disabilities needed more help with child care compared to children with other disability. But caregivers of children with learning disability had more need for help with parenting and coping compared to the other two groups, and more need for help getting information and services for their child than children with other disability. Previous research has shown that mothers and fathers of children with pervasive developmental disorders were more likely to need help than those with other diseases (Ueda et al., 2013).

It is particularly challenging to communicate with children who have intellectual, behaviour or social skills impairment. Currently in Malaysia, there are not enough centres dedicated to providing therapy for these children and children with learning difficulties tend to be neglected in public schools where the emphasis is on academic performance.

Higher severity of disability in the child was associated with having more caregiver needs in all constructs. Other studies have indicated that worse child functioning is associated with having more family needs (Perrin et al., 2000; Farmer et al., 2004; Almasri et al., 2011). The greater the child's need for extra care, the greater the need for information on community services (Hendriks et al., 2000). Better child adaptive behaviour was associated with fewer family needs for information (Almasri et al., 2011) and less need for support (Hendriks et al., 2000). Caregivers of children with more severe disability have higher care burden and more stress, since their children require more medical and health care, thus it is expected that they would need more help.

Caregivers of younger children (less than the school going age of seven) expressed more needs compared to caregivers of older children (school going age), similar to what has been found by Ueda et al. (2013). Parents of younger children reported experiencing higher levels of burden than parents of older children (Tadema & Vlaskamp, 2009), which leads to them reporting more needs related to caregiving. When the child is young, parents may require more support as they are just starting to adapt to managing their child's disability.

Child's age was not a determinant of needs in families of children with cerebral palsy (Almasri et al., 2011), and frequency of care for children with severe disabilities did not differ with age (Curran et al., 2001). But younger age of children with cerebral palsy was associated with higher unmet support needs (Gordon et al., 2012). Families of

children with severe disabilities may have ongoing needs which do not diminish or escalate with the age of the child, but higher level of perceived care burden in younger children (Tadema & Vlaskamp, 2009) could explain why they were more likely to report not receiving adequate support.

Farmer et al. (2004) found that families who were white reported fewer family needs than those from minority groups. In this study, caregiver needs did not differ by race/ethnicity, except for need for help with finances. Indians needed more financial help compared to Malays, even after controlling for education and income level. There is a possibility that Indians may have a higher propensity to express their need for financial help, but not for other types of help. A family's perceptions of their situation may differ from that intimated by the financial and educational attainment of its members (Van Horn et al., 2001). There could also be residual confounders affecting the outcome of financial needs score which were not captured in this study and therefore not controlled for.

Caregivers with lower education had more financial needs but had less need for help with coping. Douma et al. (2006) also reported lower respite care need in parents with lower education level, while Hendriks et al. (2000) did not find any association between parental education level and family needs. In this study, lower education was related to lower income level, explaining the increased need for help with finances. Lower education is associated with a higher sense of competence in mothers (Park et al., 2009), which is translated into less need for help with coping.

Our study did not find a significant association between household income and caregiver needs after adjusting for other factors, including education level. Farmer et al. (2004) and Ueda et al. (2013) found a significant association between higher number of family needs with lower income. Lower income was associated with more needs for

community services and financial needs in families of children with cerebral palsy, but was not associated with family needs for information and support (Almasri et al., 2011). The out of pocket amount families have to spend on the disabled child relative to their ability to pay would be a more suitable indicator of financial needs than income alone. Expenditure on the child with disability in turn would depend on the services or assistive devices the child needs.

Families with higher income did however express more need for help getting child care initially (before controlling for other factors). It is very probable that families with higher income consist of families where both parents are gainfully employed. When this is the case, parents need to look for a caregiver when they are at work. If one parent is not working, he/she can take care of the child but that would mean one less person to generate income for the family.

Besides family income, some studies defined socioeconomic status by occupational level. Douma et al. (2006) found higher parental occupational level to be associated with more support needs but after adjusting for other factors, this association did not remain. Hendriks et al. (2000) also found that parents' occupational level was not related to family needs.

Having more children in the family can mean having more help in taking care of the child who is disabled. The number of children in the family was not found to be related to caregiver needs in other studies (Hendriks et al., 2000; Douma et al., 2006). In this study, the difference in need for help getting child care was only between families with the least (1 – 2) and most (≥5) number of children.

Also, families with more children did not report having more or less need for help with coping or finances. A study in China found that families required less financial assistance if they had more children (Xiong et al., 2011). Parents who have more

children might experience more stress due to higher caregiving demands, but they might also cope better when they have more support from their other children. Having more children entails higher expenditure for the family's day to day needs but does not necessarily mean there would be problems financing the disabled child's care.

Japanese mothers who had more than one child with a disability were more likely to indicate needs for family and social support (Ueda et al., 2013). In this study, having more than one child with a disability was not associated with having more caregiver needs in any of the domains. It is possible that families who have had prior experience with a disabled child do not express as much needs because they have undergone an adaptive caregiving process.

Caregivers who had medical problems themselves were found to have more financial needs because they may not be able to work or they may need to spend a considerable amount of money on their own treatment.

### 5.5 Access problems to health care services

A necessary step in developing policy interventions to improve the health of children with disabilities is to identify the modifiable factors that affect health outcomes (Seid et al., 2004). Demographic and social structure is not easily changeable or altered while health beliefs have medium "mutability" and certain enabling resources have high "mutability" (Andersen, 1995). Hence, it is desirable to seek out factors related to the characteristics of community resources or service delivery which are modifiable.

The two most common reasons for unmet needs in this study were that the place of service was too far and that there was no one to send the child for therapy. The distance between the client's home and hospital can be considerable. More time is required to send the child to a facility that is located far from the child's home. The appointment time may not be suitable because most appointments are scheduled during office hours when caregivers have to work, so there is no one to send the child. Quite a high percentage of caregivers reported that they had no time to attend to their child's needs due to other commitments.

Currently in Malaysia, most rehabilitation services or therapy are still hospital based because the specialized facilities and expertise needed are only available there. Children with disabilities should ideally receive most services in their home community so that do not have to travel frequently to faraway tertiary or highly specialized health centres. In rural areas where there are limited professional services, community-based rehabilitation programmes can help meet the rehabilitation needs of persons with disabilities (Lopez, Lewis & Boldy, 2000). In this regard, the Ministry of Health's effort to have more therapists at primary health centres is a step in the right direction to have services close to the community.

Caregivers did not know where to get services/assistive devices for their disabled child, either because these services/assistive devices were unavailable and/or there is lack of information sharing about where to get them. Childhood disability does not receive as much attention from governmental agencies in Malaysia compared to other health, education and social issues. Furthermore, community awareness and support about the needs of disabled children is still lacking.

Cost of services/assistive devices was one of the main problems although services for the disabled in Malaysian public health facilities are free and assistive devices are exempted from import duty and sales tax. This suggests that families still have to produce burdensome out-of-pocket payments because existing mechanisms for financial assistance are not adequate or efficient. Besides that, it is possible that lack of availability or perceived lower quality of services for children with disabilities in the public sector induces caregivers to seek services from private or non-governmental centres, incurring higher costs.

Children with multiple disabilities are more likely to require the use of assistive devices in their daily functioning compared to children with learning disability. Unfortunately, the most cited reason for unmet need in this group of children was that caregivers could not afford the cost of assistive devices, followed by not knowing where to get them.

Assistive technology is prescribed to enhance the social inclusion of children with disabilities (Ried et al., 1995). Health providers who are involved in prescribing assistive technology need to know how to assess the child's functional status, how to use the technology once the devices are procured and how to evaluate if the technology is helping to meet the child's goals (Gaebler-Spira & Desch, 2008). Besides that, they need to know the funding sources available for obtaining devices and ways to assist families to obtain them. Legislation that promote the greater use of assistive technology

has to go hand in hand with the development of pre-service, in-service and continuing education training opportunities in assistive technology for health providers working with children with disabilities (Long & Perry, 2008).

Although Malaysia is a multi-racial country, communication problems as a reason for unmet service needs were not found to be a big issue in this study. In comparison to other countries where ethnic minorities had problems communicating with service providers (Yu et al., 2004; Ngui & Flores, 2006; Inkelas et al., 2007), in Malaysia, this problem is less encountered because most people of Chinese and Indian ethnicity can understand and speak Malay, the national language.

Around one third of caregivers of children with learning disability did not know where to seek therapy for their child, or they could not afford the cost of therapy. Besides going to school, children with learning disability in Malaysia actually can receive therapy in a number of ways. For families who can afford it, their child can attend private or NGO-run centres that provide early intervention or extra help with learning difficulties. These children can also receive occupational therapy, speech therapy and psychological services from hospitals. However, not all hospitals have these services and usually centres providing intervention for children with learning disability are only found in urban settings.

Caregivers in South Africa expressed the same reasons for the low utilization of services; lack of money, limited awareness about available services and bureaucratic obstacles (Saloojee et al., 2007). Lindsay (2010) also reported that a complex review process and gaps in funding were barriers to the procurement of communication aids.

Caregivers need more information about where to get services and assistive devices for their child, and they should be given financial assistance to pay for these services and assistive devices when necessary. Interventions to reduce these barriers can take place at the system or agency and individual levels.

At the system level, the government may come up with guidelines on coordination between health, education and social welfare services in order to pool information resources together. At the agency or individual level, a service coordinator evaluates what are the specific information needs of the family and directs or links them to available resources.

To tackle the problem of financing care, interventions at the system level include more budget allocation to subsidize the cost of services and guidelines on who and what should be subsidized, while at the agency level, the assessment of who gets and how much one gets should be tailored to the individual family. Resources cannot be allocated in a blanket manner, whereby every child with a disability gets the same amount of funding and hindered by the fact that requests for extra funding have to go through a complicated bureaucratic system.

In order to provide caregivers with more information on services/assistive devices, service providers should establish more disability support networks. A re-look at funding mechanisms is recommended to see whether qualification for financial assistance takes into consideration the family's economic situation and the extent of the child's health care needs.

### 5.6 Utilization of rehabilitation services

Utilization of rehabilitation services depend not just on the need for services but also the ease of access to those services. Severity of disability and caregivers' awareness on the need of service may determine the need for service, whereas caregivers' socioeconomic status and the social supports available to them may affect ease of access.

Only about 50% of children with learning disability used therapy services in the past one year, compared to around three quarters of children with multiple disabilities, supporting the claim that the former are a neglected group among all children with disabilities. Children with multiple disabilities also used rehabilitation services more frequently and in more facilities. This is an expected finding as children with multiple disabilities have more service needs.

A majority of children from both groups used government health care facilities. Approximately less than one fifth of children with learning disability and also children with multiple disabilities received therapy from private centres. These children are less likely to go to private therapy centres because families have to pay for services there.

More children with multiple disabilities attended community based rehabilitation centres (CBRs) compared to children with learning or other disabilities. Children with multiple disabilities such as cerebral palsy may have severe intellectual problems that prevent them from attending school and the alternative to staying at home is to attend CBRs. CBRs in Malaysia were originally set up with the aim of providing training to PWDs for independent living and generation of economic livelihood, but many have also evolved into day care centres for disabled children who have nowhere else to go.

There was an initial worry that bedridden children would be confined to the house and that their therapy needs would be neglected. On the contrary, a majority of children with disabilities in this study who were bedridden received therapy services. Around half of these children received home visits, mostly from CBR workers. However, the nature of the home visits was not probed into, whether it was to check on the health condition of the child, to offer advice on the care of the child, or to give emotional support to caregivers. Nevertheless, at least these children were in contact with either a health or social worker, who could help to facilitate care when it is needed.

Health services utilization is a function of the predisposing characteristics of the target population, the availability of enabling resources and the population's perception of their need for services (Andersen, 1995). In this study, caregiver's education level, income level and severity of the child's disability did not make a difference to the receipt of therapy among children with learning disability. This corresponds with earlier findings that level of unmet needs was not predicted by the socio-demographic factors mentioned, suggesting equitable access.

Chinese children with learning disability were less likely to receive therapy compared to Malays and Indians. This perhaps can be explained by the perceived stigma experienced by Chinese parents who have a child with learning disability, due to the Chinese culture of placing excessive importance on academic achievement. Chinese parents may be in denial of their child's learning problem and may not want to associate their child with attending therapy for learning difficulties.

On the other hand, the emphasis on academic achievement means that Chinese families who accept their child's condition seek out more avenues to help their child. More Chinese caregivers in this study send their child with learning disability to NGO centres than to government hospital compared to Malays and Indians. In Penang, NGOs such as

the Bureau of Learning Difficulties and Asia Community Service provide more structured early intervention and learning skills therapy and on a more frequent basis than government hospitals. Unfortunately, Chinese parents who cannot afford the minimal fees charged by NGOs might end up not sending their child for therapy anywhere.

Informal support was not associated with receipt of therapy but having more formal support increased the likelihood of receiving therapy. Sources of formal support include health care workers, community based rehabilitation centres and NGOs, which are also the people and places where the child can receive therapy.

There was no difference in receipt of therapy between districts in the state of Penang, indicating that there is no obvious disparity in distribution of resources for therapy or rehabilitation services. Each district has a main government hospital and at least one government health clinic providing rehabilitation services. Besides that, the NGOs also have centres on both the mainland and on the island part of the state.

### 5.7 Financial impact on the family

More children with disabilities come from families of lower income. Reports from other countries have shown that there is a tendency for households with a disabled member to be over-represented at the lower end of the income range as well (WHO, 2011).

Financial burden associated with the health care needs of children with disabilities is typically reported in three dimensions (Parish, Rose, Dababnah, Yoo & Cassiman, 2012). This study reports on all three dimensions of absolute, relative and subjective financial burden. Absolute burden is reported as the actual costs incurred by families in financing the different health care needs of CWD. Relative burden is the costs incurred

as a proportion of the family's income, while subjective burden is based on caregivers' perception of whether the costs have caused financial or employment problems.

The limitation of the reporting on absolute and relative financial burden here is that both income and expenditure amounts are best estimates provided by caregivers. There is tremendous variation in the amount of money spent for each type of care expenditure as evidenced by the wide standard deviations.

There is no information on health care expenditure among people with disabilities in Malaysia. The Household Expenditure Survey (HES) only reports on household expenditure in the general Malaysian population. Figures for households with disabled people are not available. In 2009/2010, out of pocket expenditure on health was only 1.3% of the total household expenditure (this ranged from 0.7 – 1.4 % according to socioeconomic status quintiles).

This study did not seek to find out the proportion of total household expenditure which was attributed to out of pocket expenditure on health care for the child with disability. Instead, information on the proportion of expenditure relative to the family income was obtained. In order to quantify the relative financial burden on families of CWDs, a more thorough study would have to be conducted to elicit information about expenditure for subsistence needs and the health expenditure of other family members.

For all categories of disability, the lowest care expenditures were for prescribed medicine and dental treatment. The highest care expenditures were for child care, transportation and other care expenses; not for doctor's visits, ward admissions or other allied health care services (physiotherapy, occupational therapy, speech therapy, psychologist and dietitian).

Malaysian families do not have to pay out of pocket for services and for most medicines from government health care facilities, which helps alleviate their financial burden. In the US, those who did not have health insurance were at risk of too much out-of-pocket expenditure (Newacheck et al., 2004; Kuhlthau, Hill, et al., 2005).

Nevertheless, caregivers ranked their need for help with finances highly in the Caregiver Needs Scale. Need for help paying for education/therapy was expressed most, followed by help paying for daily expenses and help paying for special equipment or toys. One third of caregivers reported the costs of services and assistive devices as reasons for unmet need. If quality is the same, caregivers would send their child to government health facilities to save on cost. But when services are not available or not satisfactory in the public sector, caregivers resort to sending their children to private facilities, incurring extra costs.

Families of children with learning disability inevitably spent more on their child's education while caregivers of children with sole vision, hearing , physical or speech disability spent more on medical devices which their child needed.

Families of children with multiple disabilities are more inclined to try alternative treatment compared to children with learning and other disability. Out of twelve types of expenditure, expenditure for alternative treatment was ranked fourth highest for children with multiple disabilities compared to ninth for children with learning disability and last for children with other disability.

Expenditure for complementary medicine was the sixth highest expenditure for both children with learning and multiple disabilities, indicating families were willing to spend on non-Western medicine or supplements if they believed it could help their child. Expenditure for ward admission was higher for children with multiple disabilities

because these children had more health problems which sometimes required acute medical care.

Relative financial burden is measured as the percentage of family income spent out-of-pocket on health care. Expenditure is defined as being catastrophic if a household's financial contributions to the health system exceed 40% of income remaining after subsistence needs have been met (Xu et al., 2003). In the Medical Expenditure Panel Survey (MEPS), Newacheck et al. (2004) defined catastrophic expenditure as out-of-pocket expenditures exceeding 5% of the family income.

In this study, slightly more than half of families spent ≥10% of their income on care expenditure for their child with disability, with 22.2% of families spending 10 – 19.99% of their income, and 32.0% spending ≥20% of their income. Families who spent a higher percentage of their income on their child's care expenditure were more likely to experience financial problems.

Because children with multiple disabilities had more service needs and need for assistive devices, a higher proportion of their families spent ≥20% of their income on care expenditure. Care expenditure increased if the child's disability was more severe, if the child was bedridden and if the child was of younger age.

Children with disabilities used more services than children without disabilities, had higher health expenditure and higher out of pocket expenditure (Newacheck et al., 2004). The higher expenditure for CWDs is congruent with their higher utilization of services. As a result, caregivers of children with disabilities faced financial problems and employment problems. According to the Australian Bureau of Statistics, having a child with disability is associated with families being more likely to suffer from financial hardship and caregivers being less likely to work or to work full time (2006).

Children with more severe conditions had higher out-of-pocket medical expenses (DeRigne, 2012). In this study, 35.2% (95% CI 29.3, 41.5) of caregivers reported having a sizable financial problem. Families of children who were bedridden, with more severe disability and who reported more service needs were more likely to have financial problems.

Children with multiple disabilities, rather than children with learning disability, were associated with families experiencing financial hardship in this study. Compared to in the US, children with mental health needs, especially autism spectrum disorders, had higher out of pocket (OOP) expenditure compared to other children with special health care needs (DeRigne, 2012). This could be explained by poor compensation systems for mental health services (Davidson, 2002) as private health insurance plans did not offer benefits for mental health conditions on par with those provided for physical health conditions (DeRigne, 2012). Different operational definitions of the population of children, types of OOP expenditure and system of financing care can account for the differences in findings.

Lower education and income levels are associated with financial hardship in caring for a child with disability. Caregivers who had none, primary or lower secondary education were more likely to experience financial problems than caregivers with tertiary education. Families with income level in the bottom 40% had more financial problem than families in the top 20%. In the US, even after controlling for health insurance, low income families still experienced greater financial burden (Newacheck et al., 2004).

After adjusting for type and severity of disability, education and income level, caregivers who were more likely to experience financial problems were caregivers with younger children, Indians, and who themselves had medical problems. This corresponds to the findings on child and family characteristics associated with financial needs on the

Caregiver Needs Scale. Indians were more likely to experience financial problems, and so were more likely to report needing more help with finances.

In this study, 53.1% (95% CI 46.6, 59.4) of caregivers reported having problems with work as a result of caring for a child with disability, with 31.4% (95% CI 25.8, 37.6) having to leave their job. Other studies reported the percentage of caregivers quitting their job to take care of their child with disability as 28.4% (Baillargeon et al., 2011) and 23.1% (Thyen et al., 2003). This study reported 40.6% (95% CI 34.5, 47.0) of caregivers took too many leave days to attend to their child's needs. The Canadian PALS 2001 found that 49% of caregivers had to work fewer hours (Baillargeon et al., 2011).

Caregivers of children who had more severe functional limitations were more likely to face restrictions in work force participation (DeRigne, 2012). Similarly, families of children with multiple disabilities, children who were bedridden, with more severe disability and who reported more service needs in this study were more likely to experience employment problems.

After adjusting for type and severity of disability, caregivers of younger children, Indians and those who had more than one disabled child were more likely to have stopped work or to have taken too many leave days to attend to their child's needs. Caregiver education level was not associated with employment problem, contrary to the finding of another study that higher parental education increases the likelihood of parental employment (Rupp & Resslerb, 2009). Caregivers in this study faced problems with workforce participation due to child related factors rather than due to parental education.

Given the costs of raising a child with disability, families would benefit from the additional income that workforce participation brings. Most mothers wanted and needed to work for pay but were prevented from doing so due to mother and child related reasons, and service system limitations (Bourke-Taylor et al., 2014). Some of the strategies to support workforce participation involving system level changes would be to provide more outside school hours care, reducing costs of child care, improving the competency of day carers and providing appropriate school supports such as disabled friendly teaching materials and teaching assistants.

It was reported in this study that 62.7% (95% CI 56.2, 68.6) of caregivers had a problem getting permission to take time off from work to attend to their child's health needs, with 20.3 (95% CI 15.6, 26.1) citing this as a big problem. Caregivers of children with multiple disabilities were the ones who faced the most problem. A national policy that offers parents of children with severe disabilities the option of taking a pre-determined duration of excused absence from work per year to attend to their child's medical needs can help parents retain their job and open up more opportunities for employment, especially in the private sector.

### 5.8 Family support

Studies have shown that better level of social support and family functioning is associated with better family well-being. Parents who were more satisfied with the social support that they received felt less distressed and depressed (King et al., 1999). Social support has been shown to reduce caregiver burden associated with having a child with more severe disability (Wijesinghe, Cunningham, Fonseka, Hewage & Østbye, 2015).

Overall, 52.5% (95% CI 45.9, 58.9) of caregivers of children with disabilities had someone to help them with the day to day care of the child. Help in the day to day care of the child mostly came from family members, particularly grandparents. Less than 10% of families relied on a domestic helper.

Family is an important social support unit and caregivers who do not have an extensive family network may receive little support. In resource constrained settings where there is lack of rehabilitation, education and welfare services for disabled children, support is mainly provided by immediate family members (Saloojee et al., 2007). Parents' support groups and disabled people's organizations may be unheard of, or few and far in between. When there is a struggle to access good formal support services, there is a heavy reliance on informal sources (Wodehouse & McGill, 2009).

This study asked caregivers about their perception of helpfulness but not the importance of support sources. Amount of support was generally rather low. All the sources of family support were generally not helpful except for the caregiver's spouse. Caregivers rated formal support as more important (Clark et al., 2012) but informal support was found to be more helpful than formal support in this study. Of course, individual differences in the personality of parents can also influence perception of care burden.

For informal sources of support, the caregiver's other children, and the child's maternal grandparents were rated as sometimes helpful. Parents of other disabled children were the least helpful, possibly because many families do not have the opportunity to come into contact with other parents. From the Caregiver Needs Scale, around 60% of caregivers expressed that they would like to have more opportunities to talk to other parents.

Joining support groups or disability related organizations is one way to meet up with other parents of disabled children, but the majority of parents in this study did not join any such organizations. Main reasons cited were that caregivers did not know of any such organizations, and they did not have time to join. Service providers do not commonly disseminate information about support groups and organizations unless caregivers enquire about them. Caregivers who have the intention to join would normally look for the organizations themselves, and make time to attend their activities. Colleagues were reported to be the second least helpful and this statement is supported by the finding that more than half of caregivers had some problems taking time off from work to attend to their child.

As for formal sources of support, school/CBR or day care centre staff and health care workers were rated as sometimes helpful. Staff from the Department of Education and Department of Social Welfare was felt to be less helpful. NGOs were the least helpful, but it is possible that not many families come into contact with NGOs in the first place, reflecting either a low demand or a limited supply of NGO services.

Families whose disabled child was of older age and who had less number of children had less informal family support. Earlier findings have illustrated that families with an older disabled child had higher level of unmet needs, and families with less children

needed more help getting child care. This shows a mismatch between needs and support available.

Among the races, Indians and Chinese had less informal family support compared to Malays, indicating that Malays have more extensive and strong informal social networks. Indians and Chinese also received less formal family support than Malays. Communication problems with service providers was one of the least cited reasons for unmet need, so it is unlikely that language barrier is the cause of this finding. It is postulated that Malays are more adept at overcoming the bureaucracy involved in dealing with government agencies.

Low and middle income families received less formal family support than high income families. The previous finding on lower income families reporting less service needs for the child was attributed to education level, but the same inference cannot be made here because education level was not associated with family support score.

Although previously it has been shown that lower income families did not have higher level of unmet needs and did not have more needs in any of the domains in the Caregiver Needs Scale, but compared to higher income families, they received less support from formal sources. The higher perception of helpfulness in higher income families may be explained by their ability to obtain more services.

The above findings indicate that health, education and social welfare agencies should be more responsive to helping lower income families and families of Indian and Chinese ethnicity. Indians especially needed more help attaining financial aid.

Children with learning disability were found to have a lower mean family support score compared to children with multiple disabilities but the difference was not statistically significant. It was expected that children with learning disability would have lower

formal Family Support score based on the findings that they tend to have more unmet needs for services. In addition, families who need more support based on their child's disability characteristics (families with children who were bedridden, who had behaviour or social skills problem and higher severity of the disability) had the same level of informal and formal support as others.

In conclusion, informal and formal sources of family support are currently not providing enough support to families of children with disabilities. Families who need support most based on their child's disability characteristics had low family support scores and did not receive significantly more family support.

Farmer et al. (2004) found a significant association between higher number of family needs with lower perceptions of social support, but Douma et al. (2006) did not find perceived level of social support to be related to met need for family support services. A community survey among elderly people in the US found that social support was not a significant predictor of health or social service use (Wan & Odell, 1981).

Although there was lack of a direct relationship between informal support systems and level of impact on the child or family, informal support was related to optimism and confidence in parenting (Bailey et al., 2007). Caregivers who received adequate social support did not have significantly higher resilience and emotional well-being than caregivers with unmet support needs, but they did report lower stress, depression and anxiety (Gordon et al., 2012).

The helpfulness of both formal and informal supports depends on the availability and quality of these supports. Informal sources commonly provide practical help with the child (such as playing, feeding or washing the child), practical help with family matters (help with housework), and emotional support, but they can also help to provide material aid and information specific to the disability. The reverse applies to formal

sources of support. Informal sources of support such as family members and friends are either available or unavailable to a family. Where informal support is inadequate, formal support services need to step in.

First of all, families with disabled children may be isolating themselves voluntarily or involuntarily, leading them to have smaller informal social networks which can help them materially and emotionally. Secondly, informal sources may not have the capacity to fully meet the higher needs for material aid and emotional support of these families. The caregiving burden and worries associated with caring for a child with disability may be difficult to relate to for others who are not in the same situation. Families of children with disabilities also tend to be poorer than families of children without disabilities. Because their informal social networks would typically comprise of poorer families as well, this reduces the amount of material aid that could be reasonably provided to them.

Family support should be a part of formal services provided (Ueda et al., 2013) in order to maximize the impact on both families and children. To assist families, services should include practical assistance to obtain information and networking such as parent resource centres, parent support groups or newsletters. In terms of assisting family functioning, service providers can help families develop problem-solving skills, coping skills and encourage family members to express emotions in a positive manner.

Interestingly, it is not the actual amount of support received, but how much parents felt supported which affects their perception of care burden (Tadema & Vlaskamp, 2009). Service providers should keep this in mind when providing help to families. It is not only a matter of having more frequent or longer duration visits or sessions, but the quality of the support is essential.

## 5.9 Strengths and limitations of study

### 5.9.1 Strengths

To the best of this author's knowledge, service equity for children with disabilities is an area which has not been studied before in Malaysia. The strength of this study is that it takes into account children with all types of disability and a diverse range of health care services.

Studies on populations of children with a wide variety of health conditions are usually in the form of national or regional surveys which entail the use of considerable resources. Smaller scale studies assessing the needs of children with disabilities or their families have been conducted in the context of primary care and specialized care such as hospital in-patient or paediatric specialty clinic settings, and early intervention or rehabilitation programmes. Most of these studies focus on specific health conditions or specific types of disability, while this study was conducted in a population context and encompasses children with all types of disability.

This study looked at both the 'demand' (needs) and 'supply' (unmet needs) aspect of service provision. A comparison of unmet needs between the different types of disability can help identify groups that may require particular attention. In order to estimate population (in this case, state-wide) parameters, weighting by type of disability was used to overcome the disproportionality of the sample brought about by stratified sampling and non-response.

Comparative analysis was not possible between all 7 categories of disability defined in Malaysia, but analysis was done by grouping children with single physical, visual or hearing disability into one group and comparing this group with learning disability and

multiple disabilities. Learning disability is the largest group of disability and thus warrants a separate grouping from other single disability.

This study provides important evidence based knowledge in the absence of other data on equity of services for children with disabilities in Malaysia. The lack of research on services for children with disabilities means that studies such as this can provide important baseline data from which to plan both services and research.

The study looks at children with disabilities as a whole, rather than choosing children with specific chronic conditions such as Down syndrome because in terms of programme planning and development, this approach has more practical usefulness. For example, when we increase the number of occupational therapy services, we are not only targeting children with Down syndrome, but all children with disabilities who need occupational therapy. Support services are therefore also not studied in a disability condition specific manner.

The needs of families caring for a child with disability vary with the child's age. For those aged less than 3 years, parents are just starting to adapt to caring for a child with disability. The caring process at this time may not be very different from the caring process of a child without disability, because all children are very dependent on their parents at this age. For those aged 3 – 6 years, the needs of the parents change according to the level of development of the child. After the age of 6, parents start to think about their child's formal education, and after the age of 12, the degree of independence the child achieves and adolescent issues come into the picture. This study chose to focus on children aged less than 12 years.

Services which address parent-identified issues will benefit families most, thus service providers are encouraged to engage families in expressing their needs. Parents serve as key informants and decision makers in the service delivery process for their children.

The concept of measuring the caregivers' perception of health needs for their child is based on the fact that parents know best what service would be beneficial to their child. Parents have indicated that they had high levels of competence and participation in making decisions about their child's health care (Schmidt et al., 2008).

Although this is a perceived need (from parents' perspective) and not an evaluated need (from professionals' perspective), it is presumed that parents would participate more in their child's intervention if they perceived the service to be of importance. Parental self-report has been criticized as a poor proxy for evaluated need of child's need for services (Warfield & Gulley, 2006), but evaluated need has to be converted to perceived need to be a motivating factor for parents to seek certain services.

Paediatricians rated the severity of the child's condition higher than parents, but the extent of unmet needs as lower (Perrin et al., 2000). They identified fewer needs of the family caring for the child with a chronic condition than either mothers or fathers, while mothers and fathers identified the same number of needs.

Primary care paediatricians underestimated parents' need for information and mothers' need for help in facilitating social contact with other families of children with chronic health conditions. They were also less likely to identify a need for genetic counselling, child care arrangements and care coordination. While parents wanted more information about their child's condition regardless of the severity and diagnosis of the child, paediatricians only recognized this need for information among children with neurologic conditions and those whose conditions have resulted in greater impact on the family (Perrin et al., 2000).

This study did not seek to compare the expressed needs between mothers and fathers although their caregiving roles may be different. Generally in many patriarchal societies, the main burden of caring for a disabled family member usually falls on one

or two female carers, whereas male members act as gatekeepers, controlling the key decisions concerning the child and associated resources (Hartley et al., 2005). Mothers are responsible for the majority of child care but most are satisfied with the division of child care labour between mothers and fathers (Crowe, VanLeit & Berghmans, 2000).

Findings on the differences in the distributions of expressed needs between mothers and fathers reveal that mothers generally expressed more needs than fathers (Bailey Jr & Simeonsson, 1988) but in some studies, this was only restricted to certain issues (Hendriks et al., 2000; Ueda et al., 2013).

Nevertheless, mothers and fathers usually agreed on what help was needed. Pilot testing of the CHC-SUN questionnaire found that fathers and mothers did not differ in their evaluation (Schmidt et al., 2007). Ueda et al. (2013) showed that mothers and fathers of the same child with disability agreed on information needs, family and social support needs, financial needs and need for help explaining to others.

Mothers and fathers of children with chronic health conditions reported a high level of agreement on the severity of their child's condition (Perrin et al., 2000). They also agreed substantially on the number and type of needs their child or family required. There was no difference in their expression of information needs, counselling needs, specific help needs such as child care and home nursing care, and total number of needs. They only differed in their perception of contact needs (discussion groups and contacts with other families), with mothers expressing more need.

Although results of this study can only be inferred to the population of children with disabilities registered with the Department of Social Welfare in Penang in the strictest sense, the registered population is assumed to be a close representation of all CWDs in the state. The service profile and access to services in other states in Malaysia is also not expected to be grossly different.

### 5.9.2 Limitations

With the limited financial and human resources available for this study, a household survey was not feasible. The aim of this study is to investigate a specific population, which is the population of disabled children. Taking the prevalence of disability in Malaysia as 1% in the total population (DSW, 2009b), only one out of every 100 households will have a disabled person and furthermore, that person can be an adult.

The study questionnaire was feasible to administer through a mailed survey but yielded a low response rate. Although response rate will be higher in studies employing face to face interview with caregivers in early intervention or therapy centres and paediatric clinics, these studies would only be able to capture children who attend those facilities. It is generally perceived that families with lower socioeconomic status would find it difficult to attend child centres. Although not all children with disabilities might be captured from the Department of Social Welfare registry, the coverage is still higher compared to taking the sample from only therapy facilities.

There is a possibility of underestimating unmet needs in the overall population of children with disabilities, because results could only be inferred to children who registered or re-registered with the Penang DSW in 2010 and later. Those who are not in the registry may be those who have not received any forms of services or assistance. Furthermore, this study was conducted in a state which has relatively many non-governmental organizations for children with disabilities. Unmet needs are predicted to be higher in states, such as those in the East coast of Peninsular Malaysia, which have few or none of such organizations.

The population studied was recruited from the Dept of Social Welfare registry, which suggests that they have already exposed or received some forms of services, information and assistance. Those who did not receive any help or who are not in the registry were

not included in the sampling frame. The data for children with disabilities could only be identified in 2011 and later. Samples might not capture children before 2011.

The response rate for this study is only 37.9% despite attempts at reminding the participants through telephone calls. It was not possible to determine whether all potential participants received the survey as not all the caregivers could be contacted. Low response rate for children with learning disability in particular, could be attributed to caregivers not seeing the relevance of the survey to them, particularly if their child only accessed education and not health services. Caregivers who had more experience or dissatisfaction with services would be more inclined to respond.

This response rate is acknowledged to be low, but comparable to other studies on services for children with special health care needs utilizing self-administered questionnaires. The mailed survey by Warfield and Gulley (2006) had a response rate of 41%. The response rate for the study by Kertoy et al. (2012) was 29.5%, even after families were mailed pre-printed reminder postcards two weeks after initial mailing. Studies that utilized self-administered questionnaires distributed directly by staff at child centres or relevant institutions also only had response rates in the region of 20 – 40% (Ueda et al., 2013; Poon et al., 2014).

Having someone to ask questions, whether through the telephone or through face to face interview would improve the response rate. However, this method is subject to interviewer bias and certain questions, for example scoring on Likert scales are better answered when self-administered. The trade-off would be to have participants complete a written questionnaire in the presence of field workers, so that they would still have the advantage of reflecting on their answers without pressure from interviewers, and at the same time participants could clarify ambiguities in the questionnaire with the field

workers. Incentives could also be provided to study subjects to enhance their participation.

There were no significant differences between respondents and non-respondents in the population of registered children with disabilities in Penang in terms of age, gender, race/ethnicity and district of residence, but more precise differences among the caregivers of these children could not be ascertained.

The results are interpreted with the knowledge that caregivers who did not complete the study questionnaire for some of the outcome variables had lower education than completers, and their children had more severe hearing impairment. The findings may be different if data collection from these two groups were to be improved.

This was a cross-sectional study, therefore conclusions of cause and effect cannot be drawn from the data. Another study limitation is that some of the explanatory and outcome variables are latent variables. Latent variables depend very much on the way they are measured, which in turn could affect the findings of relationships between variables.

Besides that, the data is respondent-dependent and self-reported. Responses depend on the subjective outlook of the respondent and may be subject to response and recall bias. This study measures perceived need from the point of view of caregivers and not evaluated need from health professionals' perspective. It has been shown that caregivers reported more needs and unmet needs than health professionals (Perrin et al., 2000).

There might be cultural factors affecting a response tendency in acknowledging needs and the propensity for self-disclosure. Asian families may perceive need for help differently due to strong cultural values of family pride and the desire to maintain personal face. It has been reported that East Asians have a tendency to give moderate

responses on rating scales (Hamamura, Heine & Paulhus, 2008; Poon et al., 2014). Malaysian families tend to report higher ratings of satisfaction with services compared to other countries (Clark et al., 2012), which could be due to cultural differences that generate a tendency to respond more favourably to questions in a survey or it could be related to the actual performance of services.

Income and expenditure values reported by caregivers in this study are approximations only. It is usually not possible to obtain exact figures from self-report as people generally do not remember them. There is also the possibility that there is underreporting of household monthly income because people are generally hesitant to disclose how much they really earn.

Data on children with chronic health conditions, who may or may not have some form of motor or intellectual impairment, was not collected as the focus is on children with disabilities. A number of studies looked at all children with special health care needs, including children with chronic health conditions and children with disabilities. Estimation of needs and unmet needs that incorporates this larger group would be different than our current estimates.

One of the limitations faced in this study is that child functioning is only rated by caregivers. Because the sampling frame for this study was obtained from a social registry, it was not possible to have health professionals assess the children's functioning. Assessment of child functioning by health professionals can be done if the study was conducted in a hospital, clinic or therapy centre setting.

There are other factors affecting the needs and unmet needs for disability related health services which are beyond the scope of this study. For example, environmental factors such as urbanisation of place of residence and physician supply were not studied. The

issue of stigma attached to disability is also recognized to be a contributing factor to the reluctance on the part of caregivers to seek services for both the child and family.

Stigma has been suggested to be prominent in Asian and African cultures, where there is a belief that disability in the child is attributed to punishment for the sins or bad deeds committed by the child's parents or ancestors (Park et al., 2009; Gona et al., 2010). Due to strong stigma and shame attached to disability, families may tend to hide their children and isolate themselves from society. Perceived stigma can reduce the perceived benefits of caring for a child with disability (Green, 2007).

In Malaysia, currently stigma attached to disability is not as strong compared to in the past. There is more awareness on disability rights and issues, with Malaysia ratifying the Convention on the Rights of the Disabled, participating in the Asia Pacific Decade of People with Disabilities, as well as with the enactment of the Disability Act.

The analysis of data collected via stratified sampling is more complex than the analysis of data collected via simple random sampling. Weaknesses of disproportionate stratified sampling are acknowledged. Even though stratification usually increases precision compared to simple random sampling, the effect of weighting in disproportionate stratified sampling is to lower the precision of some population estimates. However, it is appropriate to use complex samples analysis here in order to be able to infer to the population.

## 5.10 Conclusion of chapter five

The problem of unmet needs of children with disabilities in this study was more prevalent than that found in developed countries. Unmet need for services to tackle communication problems and behavioural problems was higher than unmet need for services that catered to visible disabilities, a common finding in other countries as well. However, while most studies found that higher severity of disability and lower income were associated with more unmet needs, this study did not. This is actually a desirable finding related to equity in health care access. The finding that caregivers of children with learning disability had more needs is consistent with the earlier finding that children whose disability was not visible tend to be neglected.

# CHAPTER 6: CONCLUSION

## 6.1 Importance of the study

Assessment of health needs is undertaken to identify unmet health care needs of a population with the aim of making changes to meet those unmet needs. It helps set priorities to improve the health of a population (in this case, children with disabilities), taking into account clinical, ethical (caregivers' perspectives) and economic considerations. This study looks at the clinical and ethical aspects. The cost-effectiveness of services or what can be afforded is beyond the scope of this study. Therefore, recommendations are made based on the first two considerations.

Health needs assessment in the population of children with disabilities provides a method of monitoring and promoting equity in the provision and use of health services in this population.

The goals and outcomes of services and supports for children with disabilities should be to help them attain their goals in participation and ensure their quality of life. Service systems should support the abilities of families and communities to meet the needs of children with disabilities. Capacity to benefit is always going to be greater than available resources but at least, an assessment of health service needs helps identify which services to prioritise. In this study, families of children with disabilities were distinguished between those who wanted services from those who did not, as well as between those who received needed services from those who did not.

Many factors contribute to the measurement of unmet needs: caregivers' perceptions of the child's abilities, their own skills and the supply of services. Awareness about the scope of service needs and the current system response to addressing these needs is

critical to understand the obstacles children with disabilities face in attempting to access health and therapy services.

## 6.2 Summary of study findings

a) Unmet needs and receipt of services

This study has shown that unmet need for health care services for children with disabilities in Penang, Malaysia was generally quite high, with certain services needing particular attention.

Dental, dietary and vision related service providers should address the needs of children with disabilities in these areas. There is a lack of personnel specializing in children with disabilities, especially in communication and psychological functioning. Speech therapy and psychological services need to be expanded. These services are especially important for children with learning or intellectual disability. Children with learning disability are a neglected group as they are more inclined to have unmet needs.

Children of school age had higher level of unmet needs, thus child specific services should not forget to include them.

A majority of children with disabilities received therapy and rehabilitation services that they need from government health care facilities. Children who were bedridden and children with learning disability and co-existing behavioural problem were more frequent services users compared to those who were not. This is a desirable finding as it indicates that children who are in need of more services were receiving them.

Chinese children with learning disability were less likely to receive therapy, possibly brought about by the strong Chinese cultural attachment to academic achievement and fear of stigma if the child is labelled as having a learning disability. Among children

who received therapy, more Chinese sent their child with learning disability to NGO centres, which provide more intensive early intervention and learning skills therapy, compared to Malays and Indians.

b) Family/caregiver needs

Services for children with disabilities should be responsive to the needs of their families and health care providers should communicate more with caregivers about the child and family's long term needs. Services are most beneficial when delivered in a family-centred manner and address issues of family support and family functioning.

Family support services have traditionally taken a backseat to medical or therapeutic services, but now family needs are increasingly being acknowledged by service providers as an essential component in managing a child with disability. The experiences of carers and the needs expressed by families can help guide the planning and implementation of programmes for children with disabilities. By understanding the circumstances of families caring for a child with disability, service providers can identify areas for improvement in the delivery of disability services.

Caregivers needed the most help getting information and services for their child, followed by help with financing their child's care. Caregivers do not need as much help for general child care. For the time being, service providers should concentrate on increasing the availability of specific services needed by children with disabilities, assisting families to obtain information about available resources, and providing appropriate financial assistance.

Caregivers of younger children and with more severe disability needed family support services most. Families of children with learning disability needed more support in the form of information and coping strategies. Financial assistance was needed most by

caregivers of Indian ethnicity, caregivers with less than a tertiary education and who themselves had medical problems.

c) Access problems

It was found that access problems were mainly related to logistics and a lack of information on resources. Lack of specialized personnel and service coverage are two main issues which health care providers in Malaysia need to tackle. Overall, the most common reasons for unmet need were that the place of service was too far and that there was no one to send the child for therapy. Approximately one third of families did not know where to go for services, could not afford the cost of services or did not have the time to ensure their child received needed services/assistive devices because they were busy with other commitments. Individual level problems with service providers, such as poor communication and previously being badly treated, were least encountered.

d) Financial impact

It was found that the highest care expenditures for children with disabilities in this study were for child care, transportation and other care expenses. Doctor's visits, ward admissions and other allied health care services were not the cause of high care expenditures. This is because Malaysian families do not have to pay out of pocket for services and for most medicines from government health care facilities.

Total care expenditure was higher if the child's disability was more severe, if the child was bedridden and if the child was of younger age. As expected, families of children with learning disability spent more on their child's education while caregivers of children with sole vision, hearing, physical or speech disability spent more on medical devices. Families of children with learning and multiple disabilities were willing to

spend on complementary medicine. In addition, families of children with multiple disabilities were also more inclined to try alternative treatment.

Relative financial burden was measured in this study. Slightly more than half of families spent ≥10% of their income on care expenditure for their child with disability. More families of children with multiple disabilities spent ≥20% of their income on care expenditure. Families who spent a higher percentage of their income on their child's care expenditure were more likely to experience financial problems.

Poverty and unemployment are additional life stressors to families caring for a child with disability. Approximately one third of caregivers in this study reported having a sizable financial problem. Around half of them reported having problems with work as a result of caring for a child with disability, with one third having to leave their job.

Families of children with multiple disabilities, who were bedridden, with more severe disability and who reported more service needs were more likely to have financial and employment problems. Lower education and income levels were associated with financial hardship in caring for a child with disability, but not with problems in workforce participation.

After taking child disability and socioeconomic factors into account, caregivers with younger children and of Indian ethnicity were more likely to experience both financial and employment problems. In addition, caregivers who themselves had medical problems had a higher likelihood of experiencing financial problems, while those with more than one disabled child experienced more problems in workforce participation.

Employment problems are attributed to child related factors rather than family socioeconomic factors. Caregivers also reported problems getting permission to take time off from work to attend to their child. Strategies to support workforce participation,

such as providing parents the option of taking a pre-determined duration of excused absence from work, and providing more disabled friendly day care or school facilities with competent and affordable carers, should be implemented.

e) Family support

Family well-being is affected by protective factors in the social environment and the extent of family-centred services. Social support systems are a coping resource that can help to reduce stress and psychological problems.

Assessment of the supports available to families shows that both informal and formal sources of family support are currently not providing enough support to families of children with disabilities. Families who need support most, based on their child's disability characteristics, did not receive significantly more family support. Only families with a disabled child of younger age and with more children were found to receive more support from informal sources.

In order to maximize the impact on families and children, provision of social support services to families is highly advocated. Having more formal supports from governmental agencies and non-governmental organizations was associated with an increased likelihood of receiving therapy.

Formal support services are particularly essential when informal supports are weak, as has been found in lower income families, and families of Indian and Chinese ethnicity. Unfortunately, the findings show that these families were also the ones who received less formal support. Health, education and social welfare agencies should therefore make their services more accessible to lower income families and families of Indian and Chinese ethnicity.

f) Equity in access

Children of younger age were in need of more health care services and family support services. However, they had lower level of unmet needs and received more informal support.

Children who need services most based on their disability characteristics, were able to access services. Children with multiple disabilities and with more severe disability were not found to have higher level of unmet needs. Unmet needs were not associated with income or education level, meaning children from socioeconomically disadvantaged families were not prevented from accessing services. Furthermore, caregiver's education level and income level did not make a difference to the receipt of therapy among children with learning disability.

The mechanisms of health care delivery and financing for people with disabilities are crucial in making sure children with disabilities can access services and equipment that they need. Based on this study's findings, access to the current Malaysian health system can be considered quite equitable. If Malaysia implements social health insurance under its health care reform instead of relying on the current tax based financing system, serious thought should be given on who to cover, what to cover and how much to cover for CWDs.

Although health care of CWDs will be subsidized, but the extent to which subsidies will be provided (for example whether co-payment is needed, what disability services are included in the benefit package, whether services in the private health care sector will also be covered) should be thoroughly considered before implementation. While the aim of all health care systems is to maximize care while containing costs, cost-effectiveness is sometimes secondary to the rights of vulnerable groups.

### 6.3 Public health significance and implications

This study can be used to inform health service providers and those involved in policy reform about the appropriateness of existing services and to help identify areas for setting priorities. Recommendations can be integrated into the planning and development of disability services. The findings can be helpful in suggesting some policy directions and increase service support opportunities through expansion of current services or the addition of new ones.

In tandem with the Plan of Action for the Health Care of PWDs, public health and hospital services should be made complementary and seamless, rather than overlapping, to optimize resources without compromising accessibility.

Planning of health services should match the unmet needs of children with disabilities and their caregivers. Areas of greater or lesser needs are identified to give direction for further exploration of gaps and redundancies in services, and to align resources. An unmet need for a particular service could be due to the service genuinely not being available, due to families not being aware that the service is available, or due to families having difficulty accessing the services even though they are aware that it is available.

Services for children with disabilities should go beyond the traditional core services of physiotherapy or occupational therapy, to also address the psychosocial needs and the development of parenting or advocacy skills of caregivers. Services should assist families to obtain information about community services and resources available for their child, and should assist families in navigating the complex system of services.

The needs of families of children with disabilities are varied and certain family needs can be highly specific to individual families, but some form of systematic assessment is helpful to guide family support and interventions. The Caregiver Needs Scale can be

used as a supplementary tool to identify family support services that need strengthening at the individual family, agency and even system level. The study also provides information about which groups of families with disabled children are likely to need more help.

Priority areas identified through this study are first presented, followed by recommendations on how to improve services for children with disabilities and how to overcome problems with disability data in Malaysia.

### 6.3.1 Priority areas

This study highlights the types of paediatric disability services which the government should invest more money and staff development on.

Health care which is not directly related to the child's disability tends to be overlooked. This is evidenced by the high need and unmet need for dental and dietary services for all children with disabilities. It is recommended that children with disabilities be provided with regular dental care and dietary advice. Health care workers should look out for dental and dietary problems in children with disabilities besides looking for other more obvious medical problems.

Children with disabilities other than visual disability also had high unmet need for visual assessment and vision aids such as spectacles. Vision related services and aids are more unmet compared to hearing related services and aids. This calls for a comprehensive review of the reasons for delay or non-provision; whether there is a shortage of paediatric ophthalmologists and optometrists, and whether there are funding difficulties in the procurement of visual aids.

In addition, an in-depth look at the availability of specialized personnel, especially in the fields of communication and psychology, is warranted. Lack of expertise can lead to lack of proper early assessment and intervention of communication, learning and behavioural problems.

The finding that there are high unmet needs for speech therapists and communication aids shows that helping children with communication problems is an area that needs more attention. This study also found a high prevalence of unmet need for psychological services. The lack of child clinical and educational psychologists in Malaysia means that the role of prescribing psychological interventions such as cognitive behavioural therapy will have to be taken up by doctors and occupational therapists.

The Ministry of Higher Education should encourage institutes of higher learning to allocate more places for psychology, speech therapy and occupational therapy diploma and degree studies. The Ministry of Health in turn, should create more job positions for psychologists and therapists in public service. While waiting for more psychologists and therapists specializing in managing child disability to enter the job market, existing doctors and therapists have to continually update their knowledge on psychological and communication interventions, as they are the ones whom parents will be looking to for help. In addition, there should be good communication between hospital and community health service providers regarding home nursing services needed by children with disabilities who are medical technology-dependent.

This study also informs on which groups of children with disabilities and their families who are likely to need more help. An increasing number of children are being diagnosed with learning disability. The results show that children with learning disability had more unmet service needs, as well as more caregiver needs for information, help with child

care and coping. Furthermore, a smaller proportion of children with learning disability utilized therapy services compared to other children with disabilities.

People with physical disability have rehabilitation specialists, those with visual disability have ophthalmologists, those with hearing disability have ear, nose and throat (ENT) specialists, and those with mental disability have psychiatrists. However, people with intellectual disabilities are seen by physicians or paediatricians who may have very little competency in the area. Expertise in managing children with learning disability can be increased through pre- or in-service training. Besides that, people with intellectual disabilities need to be more visible so that the demand, and subsequently the supply of health and education professionals who specialize in dealing with intellectual disabilities will also increase accordingly.

Malaysia has ratified the Convention on the Rights of the Child, which states that every child has a right to education. The Ministry of Education should take a hard look at providing more funding and teacher resource support to schools providing inclusive education and special education integration programmes.

Older children were found to have higher level of unmet needs, while families having a disabled child of younger age had a higher likelihood of financial and employment problems and expressed more caregiver needs. Child specific services should not forget to include older children, while formal family support services are needed most when the child is young. The need for formal support services in younger children is however mitigated by the fact that they receive more informal family support.

The findings that children with learning disability and children of school age experience more unmet needs is the basis for recommending schools to play a bigger role in securing the health of these children. The school setting is conducive for screening and evaluation of health needs as it is the child's natural learning and social environment.

Children with learning disabilities have been found to be more prone to emotional and behavioural difficulties (Pastor & Reuben, 2009), thus it is recommended that school health authorities focus on the unmet mental health service needs of children in special education.

Families of children with more severe disability had more caregiver needs, but were not more likely to receive informal or formal support. This indicates that family support services should target children with more severe disability, regardless of the type of disability and age of the child.

Caregivers with lower education were less likely to recognize their child's need for services/assistive devices, and needed more help with finances. And although lower income families did not report more unmet needs, caregiver needs, or financial and employment problems, they were found to receive less formal support.

Responses to overcome access problems in families of children with disabilities should still target those with low income and less education. Those with lower education should have their child's condition more thoroughly explained to them, while those with lower income should be given more support by health, education and social welfare authorities. Having said that, lack of education is highly associated with low family income, so there may be no distinction in which families to assist more in terms of overall support.

Although this study did not find that children from socioeconomically disadvantaged families were prevented from accessing services in the current Malaysian health system, the lack of health and education professionals in the government sector who are competent in managing childhood disability, especially for learning and communication difficulties, forces families to seek services from the private sector or non-governmental organizations. Families who cannot afford to pay for private or NGO services are the

ones who will face problems getting needed services for their child if the quantity and quality of services in the government sector is lacking.

Caregivers of Indian ethnicity were more likely to have financial and employment problems as a result of taking care of a child with disability, and were more likely to report financial needs, even after adjusting for education and income level. They also received less informal and formal support. Hence, welfare officers should be more alert to the financial situation of Indian families caring for a child with disability and try to provide financial help if required.

### 6.3.2 Recommendations to improve service provision for children with disabilities

To overcome challenges in providing services to children with disabilities, studies and reviews have stressed the importance of developing community based disability related services, training of personnel and increasing inter-sectorial collaboration through care coordination.

a) Recommendations to advocate and increase priority for children with disabilities

Money and staff allocation goes to other public health services when the demand for disability services is low. However, demand is also driven by supply. Caregivers may not ask for services if the services are not available or are of poor quality. Thus, health literacy for caregivers of children with disabilities, especially those with lower education level, is important. This study found that caregivers of lower education level expressed less service needs for their child. When caregivers know about their child's health needs and the services which can help meet those needs, the demand, and also the supply for disability related services will increase.

In Australia, the transition in caregiving of people with intellectual disabilities from primarily registered nurses who specialized in the area, to often non-registered disability care workers, family or friends resulted in the intellectual disability theme becoming invisible in the student nursing programme (Goddard et al., 2008). There was a fall in the number of registered intellectual disability nurses, meaning there were less nurses with skills, knowledge and commitment to care for people with intellectual disabilities.

Health service providers, be it nurses or doctors, are more attracted to conventional medical or surgical expertise areas. Both doctors in hospitals and health clinics see a myriad of health problems and even if they have the inclination, they do not have the time to focus on children with special needs. To get health care providers interested and willing to work in disability care, there needs to be a conscious effort to highlight disability issues in health care.

There are implications on the education and on-going training of health care providers from this study. The need for more information and the need for care coordination mean that health care providers should receive training on how to carry out the roles of information provider and care coordinator. The disability theme needs to be visible in all health care specialization training programmes.

Care coordination is an area that especially needs consideration for resource allocation. Care coordination functions such as determining eligibility for services, identifying and arranging evaluations, providing support to families, making referrals to outside agencies, exchanging information among service providers and families, maintaining follow-up contact and determining discharge from services entails time and financial costs (Jackson, Finkler & Robinson, 1995). The one to one contact and large knowledge base required makes it necessary to invest in resources to produce skilled professionals who can effectively carry out the tasks of care coordination (Lindeke et al., 2002).

Unfortunately, care coordination services tend to be valued less than direct clinical services and may not be recognized as an important component of paediatric rehabilitation services. If health care providers are to be paid by social health insurance financing mechanisms, they need to be reimbursed for additional work involving care coordination.

b) Recommendations to reduce gaps in quantity and quality of services

Rehabilitation services were first introduced in primary health centres in Malaysia in 1996, and are gradually expanding. However, there is still a need for more rehabilitation services in places which are located far from hospitals. This may involve the creation of a permanent therapist post in the area or coverage by a visiting therapist who is based elsewhere. Visiting therapists should be the same person as therapy is a continuous process, and the particular person should be reimbursed for their work as it entails travelling inconveniences. Because the visiting therapist may not be able to service an area which is remote as frequently as he/she can in urban settings, it then becomes important for parents and community workers to be trained on how to handle either the individual child or children with similar conditions in general. Other limitations faced include lack of space and equipment for therapy activities in health clinics.

More children were referred for therapy if it was made available at the community level and generally there is a greater willingness to accept treatment if it is locally provided (Nesbitt et al., 2012). Saloojee et al. (2007) proposed that strategies targeting children with disabilities in impoverished settings should be addressed at the district level, because many basic needs could be met in the community and do not require highly specialized personnel.

In one such successful community based rehabilitation programme in Fiji, the implementation of competency based training, assessment, consultancy and local/community participation activities was shown to produce positive outcomes (McIntyre et al., 2009). The programme helped in developing the skills of community rehabilitation assistants (CRAs), health workers, parents and teachers. All stakeholders reported high satisfaction with the programme and recommended training more people and increasing the number of CRAs. As a result of the programme, children with disabilities were provided with detailed action plans with functional goals. Participants even felt that community perception of disability had changed for the better.

Besides training community rehabilitation workers, training packages for parents on how to care for their child within their own community settings has also been suggested. McConachie et al. (2001) found that distance training packages along with mother-child groups were beneficial in improving maternal knowledge about disability-related services.

Parents can play a larger role in making sure their children get needed services as they are valuable sources of information themselves. Parents of children with intellectual disabilities expressed a need for parents themselves to be involved as trainers for future service providers (McConkey et al., 2006). In addition, caregivers of disabled children could be trained and employed by district services to facilitate links between governmental service providers and other caregivers of children with disabilities.

It is beneficial for parent and youth facilitators to be included in children rehabilitation teams (Gibson et al., 2009). A parent to parent service model of operation was established in New Zealand whereby parents who themselves have children with special needs undergo training and offer a telephone counselling service to support other parents (Hornby, Murray & Jones, 1987).

There is a need to train more therapists for the successful inclusion of children with disabilities in their natural environments. Parents preferred getting information about their child's condition directly from a professional (Sciberras, Iyer, Efron & Green, 2010). Families also wanted partnership with health professionals and wanted health professionals to advocate for their child (King et al., 2008; Roy et al., 2008; Fereday et al., 2010).

The holistic approach to the care of a child with disability means addressing broader issues requiring involvement from health care providers beyond what they have been used to doing. In fact, it is getting more essential for health care providers to participate in outreach programmes, providing not just services, but also information, and facilitating support networks for caregivers. Favourable characteristics of service providers are those who understand the impact of disability on the family, develop partnerships and establish good communication with families. Skills needed by health care providers include the ability to assess the child's needs in the child's environment, collaborating with parents and caregivers, and designing an individualized programme which incorporates family needs (Harrison, Able-Boone & West, 2001).

Even if children can be directed to the relevant service providers, many specialty areas still lack expertise on child disability. The reality is that most health care professionals have little training in assessing family needs or providing family centred services. Questions from parents of CSHCN during visits to primary care physicians were more likely to be unanswered than questions from parents of children without special needs, with inadequate information resources being cited as one of the main reasons for not pursuing answers to the questions (Norlin, Sharp & Firth, 2007).

Primary care physicians were not well equipped to manage children with developmental disabilities but they were expected to know about complementary and alternative medicine and about supports available in the community (Liptak et al., 2005). Primary care physicians were rated highly on their ability to keep up with new aspects of care and their sensitivity to the child's needs but they had the lowest ratings for linking parents with other parents of children with similar conditions, understanding of the impact of the child's condition on the family and ability to answer questions about the child's condition (Liptak et al., 2005). Families of children with autism in particular reported more dissatisfaction with their primary care physicians on several aspects of care.

Although primary care service providers may not have adequate knowledge and experience to deal with relatively rare disabilities, they play a central role in directing families to appropriate specific care services. In the UK, general practitioners provide primary health care to children with disabilities, make referrals and coordinate other health care services, but may be inadequately trained for this role (Tracy & Henderson, 2004). Community child health doctors were found to have a clearer idea of their role of regular reassessment, education assessment and interagency liaison compared to general practitioners (Ni Bhrolchain, Klein & Smith, 1993).

Primary care physicians in Malaysia typically refer to family medicine specialists or medical officers in government health clinics or general practitioners in private practice. But the predominant health care provider for children with disabilities is usually the general paediatrician based in the hospital. In contrast, primary care for children with special health care needs in the US is provided by a general paediatrician who is part of a paediatric practice in the community.

The traditional role of the general paediatrician seeing children with disabilities requires them to just prescribe needed medication and refer children to relevant therapists. However, general paediatricians can no longer ignore the additional roles of coordinating and advocating for families of children with disabilities.

In Malaysia, there is still a lack of expertise addressing the specific needs of children with developmental disabilities. For example, although there are many paediatricians, not all have the interest or expertise to manage a child with autism or dyslexia. Currently, developmental and community paediatricians are the more qualified physicians to guide families regarding therapy.

The general paediatrician is more suited to the role of overseeing the child's overall health care but in Malaysia, this role is usually restricted to the hospital environment. Doctors in hospital usually only refer the child to specialized therapies in the hospital itself, although the hospital may be located far from the child's home and it may be inconvenient for caregivers to travel frequently. To overcome this problem, it is recommended that hospital based health care providers are exposed to community based services through joint training with community health care providers.

Services in the community should be on par with those offered in hospital or by private therapists, thus there should be continuing education and training opportunities for therapists who are sent to work in health clinics. Not all therapists placed at health clinics have received adequate training to handle children with disabilities. Besides that, these therapists cannot be expected to know all the treatment modalities for different types of disability. One solution is to have these therapists learn the required individual intervention for the child from the hospital therapists and implement it when the child is back in his/her home community.

Although most assistive technology needs are identified by physical, occupational or speech therapists, primary care physicians and paediatricians can benefit from additional expertise in this area (Peredo et al., 2010), as they are often asked to give their input about the child's capacity to benefit from the technology. District or state health authorities need to get feedback from therapists and physicians directly involved in prescribing assistive technology so that they can advocate for more funding or changes to policy that make the technology more readily obtainable.

The problem of finding a service provider with skills is not eliminated by increases in health care financing (Warfield & Gulley, 2006). Hiring more service providers and reimbursements for care coordination work is important, but making sure these providers have the necessary skills for their work should also be a top priority.

All service providers, be it health, education or social workers, are encouraged to assist families in accessing various services by sharing information about low cost resources. Teachers are an invaluable source of information related to teaching and training a child with disability, and in some cases, are far more accessible. Children spend a majority of their time in school, compared to health care facilities where encounters are brief and spaced out. Social workers can provide important information on finance related issues. Family counsellors or psychologists can provide strategies or consultation to support families going through challenging relationships.

It is usually not possible to spend a lot of time teaching the skills needed for dealing with children with disabilities in the undergraduate curriculum of nurses, therapists or teachers, considering the amount of topics that need to be covered in the whole syllabus. Thus, in-service or on-the- job training is crucial.

In Malaysia, rehabilitation for children with disabilities is also provided by Community Based Rehabilitation centres (locally known as PDK or *Pusat Pemulihan Dalam Komuniti*) sponsored by the Department of Social Welfare. These centres are run by community rehabilitation workers who are not academically qualified therapists. With the MOH providing outreach services to these CBRs through the 1Malaysia Family Care programme, there is actually a window of opportunity for training programmes involving both health and CBR workers.

c) Recommendations to improve care coordination

Children with disabilities or special needs require a multitude of health, education and social services. Care coordination will become increasingly important in health systems as more children with acute and chronic conditions survive and move from hospitals to community-based care systems. Unfortunately, research has shown that children with more severe disability who were in need of the most help were more likely to have their care poorly coordinated (Warfield & Gulley, 2006; Nageswaran & Farel, 2007). Caregivers in this study ranked needing help with care coordination as sixth highest out of 20 items in the Caregiver Needs Scale, with 56.4% (95% CI 49.9, 62.7) of them definitely needing help getting care coordination.

Coordination of services for children with disabilities can be looked at from two aspects: coordination between different service providers within the health system itself, and coordination between systems of health, education and social welfare. Within the health system, there should be coordination between hospital and primary care services, as well as between different specialties.

Children with disabilities are admitted to hospital for treatment during acute events and discharged home when they recover. Where there are clear administrative demarcations in hospital and community health services, linking the two poses a great challenge. Both general practitioners and community child health doctors in the UK complained of poor communication with each other and with hospital services (Ni Bhrolchain et al., 1993).

Because of frequent visits to specialists, children with special health care needs often do not use primary care clinic services. However, specialty clinics tend to focus on the child's illness-based problems and overlook general developmental, non-disease related issues. Specialty providers are not educated to provide care outside their identified specialty and lack the knowledge of resources available in the child's home communities.

In Malaysia, a child with special needs does not have a designated primary care physician. A child suspected to have disability who is detected at the primary care level is always referred to the paediatrician in the hospital. The child seldom goes back to see the doctor at the health clinic and there is seldom any direct feedback from the hospital doctor to the health clinic doctor in the community.

Besides that, patients often see different doctors during different visits to the paediatric clinic, ranging from house officers to medical officers to specialists. The only time the child sees the same doctor is if he/she is managed by a sub-specialist or if it has been explicitly expressed for him/her to see the same doctor. Because of the 'different doctor each visit' scenario, a doctor who is not going to have regular contact with the child will not be inclined to spend too much time on care coordination tasks.

Key worker programmes have been found to be helpful to both parents and health professionals in this regard (Rahi, Manaras, Tuomainen & Hundt, 2004; Farmer et al., 2005). These programmes serve as a community link, whereby either a hospital or

community based key worker, usually a nurse practitioner or medical social worker who is part of a specialty team, provides information and facilitates access to specific services both in hospital and in the community, provides emotional and social support to families, and facilitates meetings with other families of children with similar conditions. In the US, recognition of the dilemma in meeting children's primary care as well as specialty care needs has resulted in the Medical Home project where care is coordinated (usually in a general paediatric primary care practice).

In addition, health professionals should work in coordinated teams to facilitate provision of services. In countries such as UK and Finland, there are multidisciplinary teams who look after a child with special needs. The team comprises the primary health care provider, relevant specialists and therapists related to the child's disability, psychologists, and also non-medical service providers such as teachers, social workers and home advisors.

The idea of a multidisciplinary team (MDT) for a child with special needs has been introduced in Malaysia, but not implemented in a holistic manner. Currently, the personnel who make up the MDT are doing their job separately without much consultation with each other. There is no case conference whereby the child's problems are discussed with other members of the MDT. Each health personnel seeing the child may conduct their own needs assessment and have a management or intervention plan for the child, but this is not consolidated in a single Child Care Plan. Despite contact with different service providers, the lack of coordination renders care for these children to be fragmented. Education and social welfare needs are also often not addressed.

One of the recommendations to overcome the problem of lack of care coordination is to establish multidisciplinary teams who actually meet up to discuss the child and family's needs, and come up with solutions to meet those needs. A comprehensive needs

assessment taking into consideration not just the child's medical problem, but also the home and school environment should be undertaken. Needs assessment and service coordination arrangements should be specified in local protocols and action plans. A specific person should be assigned as the child's service coordinator or else, no one will take on this overarching responsibility.

The relationship between parents and health care providers in Malaysia is still very much provider-centric, meaning families rely heavily on the assessment and effort of health care providers to make sure their child gets services that are needed. Currently, because there is no specifically designated service coordinator, parents face the daunting task of figuring out how to navigate the different health, education and social systems on their own.

Parents should understand service delivery systems and communicate with service providers about their needs (O'Neil et al., 2008), but this is not the scenario locally. While caregivers are expected to take initiatives to help themselves instead of waiting for help to come to them, some families actually lack the capacity to do so due to poverty or poorer social support. In a US study, access to care coordination in a medical home was lower for children whose mothers had less education and who were living in poverty (Nageswaran & Farel, 2007).

Having said that, health care providers, whether in the hospital or primary health care setting, lack the training to coordinate the child's care outside their area of expertise. For example, they may not know what are the social benefits the child is entitled to, what are the necessary procedures to go about obtaining those benefits and what are the community agencies that can help the family. If key worker programmes are set up, staff identified as key workers need to be trained for care coordination work

In the meantime, service coordination can be performed by any health, education or social care professional. More collaborative service and training programmes between agencies would expose care workers to different aspects of caring for a child with special needs.

### 6.3.3 Recommendations to overcome problems with disability data

National surveys with dedicated attention to childhood disability have yet to be conducted in Malaysia. Ideally, a more accurate prevalence of childhood disability should be established first through a population census. Once the census identifies the population of children with disabilities in the country, a nationwide child disability survey addressing issues of service equity can be undertaken. Geographical variability can then be examined by comparing the performance of different jurisdictions.

In view of the introduction of an electronic information management system for persons with disabilities, and the change in classification of categories of disability, the DSW has embarked on a re-registration exercise to get all persons with disabilities to re-register online since 2010/2011. This exercise is still in progress and with this, it is hoped that an accurate, up to date database of persons with disabilities can be available, where data can be extracted for research or policy planning purposes.

The national registration system for PWDs should have mechanisms in place that make allowances for turnover of numbers due to death, change in disability status or the movement from one age group to another. The establishment of an integrated database for children with disabilities is warranted, maintained by DSW but linked to MOH and MOE. This database should be comprehensive by containing not just sociodemographic data, but also health and education data on children with disabilities. The existence of

such a database would greatly help in analysing the needs of the target population in order to enable effective policy formulation and programme implementation.

### 6.4 Recommendations for future research

Unmet needs of services for caregivers can be measured by further asking caregivers to rate their receipt of services (fully received, received but not enough, not received at all). The current study's emphasis was on what are the services families wanted, and not on whether service provision was adequate. Future studies could tackle this issue.

Although this study did ask why children did not get the services that they needed, the extent of problems accessing services can be further explored. The format in the European Child Health Care – Satisfaction, Utilization and Needs questionnaire can be adopted, whereby parents were asked to rate the difficulty accessing a particular service using a 5-point Likert scale with responses ranging from 'extremely difficult' to 'not difficult'.

A new instrument (the Caregiver Needs Scale) was developed to assess the needs of caregivers of children with disabilities. The CNS showed satisfactory psychometric properties but further examination is warranted to confirm its validity. Future studies can be undertaken to confirm the validity and utility of the scale for caregiver needs assessment in Malaysia and in other Southeast Asian countries.

Programmes for information provision, support and liaison by key workers in specialized centres have not been widely implemented and studied although they have been advocated based on their potential to facilitate coordination of health, education and social services (Rahi et al., 2004). Implementation of key worker programmes in Malaysia may be an area of future study, while at the same time providing intervention in the form of service coordination for children with disabilities.

Services for children with disabilities can be examined from the aspect of Structure (are the services structured to meet the child and family's needs), Process (how family-centred are those services or the quality of care provided by those services) and Outcome (whether the services have contributed to child or family outcomes that enhance participation and quality of life) (Dickens et al., 2011).

In this study, quality of health care services and satisfaction with care was not directly measured. The focus was on needs assessment to gain an understanding of what services are important to children and families living with disability, rather than how 'good' these services are. When services for children with disabilities and family support services become more established, the next step would be to measure the quality of care of these services and families' satisfaction with these services.

Quality of care impacts on health outcomes and differs according to the institution and the people giving the services. Information on quality of services and satisfaction with care from the consumer's perspective can help health care providers and policy makers gauge the performance of the health system (Schmidt et al., 2008). Client satisfaction is a major interest of health managers overseeing services in hospitals, clinics, rehabilitation centres and other care related institutions. Satisfaction can be measured for one-time encounters with service providers or for on-going services for children with chronic conditions.

As family-centred care has been endorsed for all children with special health care needs, research on the family-centeredness of services can be a topic of future work. Although there are variations in the findings on outcomes of family-centred services depending on the type of child condition and the measurement tools used, in general, more studies showed family-centred services contributing to improved child health status and family

well-being, and increased satisfaction with services (King et al., 1999; Law et al., 2003; Kuhlthau, Bloom, et al., 2005).

If Malaysia embarks on a national child disability survey, the issue of service equity can be tackled on a larger scale. Future studies can delve deeper into problems with access to services and quality of care, focusing on the structure and process elements of service provision. Measurement of child and family health outcomes and satisfaction with services is recommended when interventions such as key worker programmes are put in place, or as a means of comparing the health system over time.

As a conclusion, this study has contributed to (i) the learning of the needs and priorities in the population of children with disabilities, (ii) highlighting the areas of unmet need and providing recommendations to work towards meeting those unmet needs.

Findings from this study can be used to improve health care and support service provision for children with disabilities and their families. There needs to be more vigorous development of specific rehabilitative services and the mechanisms of financing delivery of those services, as those are the needs most frequently expressed by caregivers. Service providers and those involved in policy reform may consider prioritising specific services drawing upon the findings of this study.

Clearly, a lot more can be done to improve services for children with disabilities in Malaysia to achieve the level of care in developed countries. Children with disabilities and their families have the right to the best quality of life possible for them, and health care and family support services should be there to help them achieve this right.

References

Aburahma, S. K. (2011). Dental problems and barriers to dental care among children with disabilities in northern Jordan. *Developmental Medicine and Child Neurology, 53*: 18-19.

AIHW. (2006). Disability updates: Children with disabilities (Vol. 42): Australian Institute of Health and Welfare.

AIHW. (2014). Disability support services: Services provided under the National Disability Agreement 2012-2013 *AIHW bulletin* (Vol. 122 Cat. no. AUS 182). Canberra: Australian Institute of Health and Welfare.

Akmese, P. P., Mutlu, A., & Kayhan, N. (2012). Perceptions of family needs in mothers of children with physical disabilities. *Procedia - Social and Behavioral Sciences, 46*: 1122-1124.

Almasri, N. A., Palisano, R. J., Dunst, C. J., Chiarello, L. A., O'Neil, M. E., & Polansky, M. (2011). Determinants of needs of families of children and youth with cerebral palsy. *Children's Health Care, 40*(2): 130-154.

Amar-Singh, H. (2008). Editorial: Meeting the needs of children with disability in Malaysia. *Medical Journal of Malaysia, 63*(1): 1 - 3.

Amar-Singh, H. (2013). *Overview of initiatives & programmes, key challenges & obstacles to the full realisation of rights of children with disabilities in Malaysia.* Paper presented at the UNICEF round table discussion on children with disabilities, KL, Malaysia.

Andersen, R. M. (1995). Revisiting the behavioural model and access to medical care: Does it matter? *Journal of Health and Social Behaviour, 36*: 1-10.

Bailey, D. B., Jr., Nelson, L., Hebbeler, K., & Spiker, D. (2007). Modeling the impact of formal and informal supports for young children with disabilities and their families. *Pediatrics, 120*(4): e992-1001.

Bailey Jr, D. B., & Blasco, P. M. (1990). Parents' perspectives on a written survey of family needs. *Journal of Early Intervention, 14*: 196-203.

Bailey Jr, D. B., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. *The Journal of Special Education, 22*(1): 117-127.

Baillargeon, R. H., Bernier, J., & Normand, C. L. (2011). The challenges faced by caregivers of children with impairments of psychological functions: A

population-based cross-sectional study. *Canadian Journal of Psychiatry, 56*(10): 614-620.

Beecham, J., Chadwick, O., Fidan, D., & Bernard, S. (2002). Children with severe learning disabilities: needs, services and costs. *Children & Society, 16*: 168 - 181.

Benedict, R. E., & Farel, A. M. (2003). Indentifying children in need of ancillary and enabling services: a population approach. *Social Science and Medicine, 47*: 2035 - 2047.

Betz, C. L., Baer, M. T., Poulsen, M., Vahanvaty, U., Bare, M., Haddad, Y., & Nwachuken, G. (2004). Secondary analysis of primary and preventive services accessed and perceived service barriers by children with developmental disabilities and their families. *Issues in Comprehensive Pediatric Nursing, 27*: 83 - 106.

Boss, P. (2002). Definitions. A guide to family stress theory. Family Stress Management. A Contextual Approach (2nd edition) (pp. 10 - 28). California, USA: Sage Publication, Inc.

Boudreau, A. A., Perrin, J. M., Goodman, E., Kurowski, D., Cooley, W. C., & Kuhlthau, K. (2014). Care coordination and unmet specialty care among children with special health care needs. *Pediatrics, 133*(6): 1046-1053.

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2014). Complementary, alternative, and mainstream service use among families with young children with multiple disabilities: family costs to access choices. *Physical & Occupational Therapy In Pediatrics*. *35* (3): 311-325.

Bramlett, M. D., Blumberg, S. J., Ormson, A. E., George, J. M., Williams, K. L., Frasier, A. M., . . . Wang, F. (2014). Design and operation of the National Survey of Children with Special Health Care Needs, 2009-2010. *Vital And Health Statistics. Ser. 1, Programs And Collection Procedures* (57): 1-271.

Brodin, J., & Lindstrand, P. (2005). Parents' needs of respite care - A discussion based on a literature review. *Eurorehab, 15*(1-2): 5-14.

Bujold, C., Swan, J., & Taylor Baer, M. (1998). Access to nutrition services under managed care for children with special health care needs. *Journal of the American Dietetic Association, 98*(A61).

Carroll, C. (2010). ‘‘It’s not everyday that parents get a chance to talk like this’’: Exploring parents’ perceptions and expectations of speech-language pathology

services for children with intellectual disability. *International Journal of Speech-Language Pathology, 12*(4): 352 - 361.

Chadwick, O., Beecham, J., Piroth, N., Bernard, S., & Taylor, E. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? *Child and Adolescent Mental Health, 7*(2): 66 - 72.

Clark, M., Brown, R., & Karrapaya, R. (2012). An initial look at the quality of life of Malaysian families that include children with disabilities. *Journal of Intellectual Disability Research, 56*(1): 45-60.

Clark, P., & MacArthur, J. (2008). Children with physical disability: Gaps in service provision, problems joining in. *Journal of Paediatrics and Child Health, 44*: 455 - 458.

Crowe, T. K., VanLeit, B., & Berghmans, K. K. (2000). Mothers' perceptions of child care assistance: the impact of a child's disability. *The American Journal of Occupational Therapy, 54*(1): 52-58.

Curran, A. L., Sharples, P. M., White, C., & Knapp, M. (2001). Time costs of caring for children with severe disabilities compared with caring for children without disabilities. *Developmental Medicine and Child Neurology, 43*(8): 529-533.

Davidson, E. J., Silva, T. J., Sofis, L. A., Ganz, M. L. & Palfrey, J. S. . (2002). The doctor's dilemma: challenges for the primary care physician caring for the child with special health care needs. *Ambulatory Pediatrics, 2*: 218-223.

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability, 34*(2): 153-162.

De Jongh, A., Van Houtem, C., Van Der Schoof, M., Resida, G., & Broers, D. (2008). Oral health status, treatment needs, and obstacles to dental care among noninstitutionalized children with severe mental disabilities in the Netherlands. *Special Care in Dentistry, 28*(3): 111-115.

DeRigne, L. (2012). The employment and financial effects on families raising children with special health care needs: an examination of the evidence. *Journal of Pediatric Health Care, 26*(4): 283 - 290.

Desai, M., Messer, L. B., & Calache, H. (2001). A study of the dental treatment needs of children with disabilities in Melbourne, Australia. *Australian dental journal, 46*(1): 41-50.

Dickens, K., Matthews, L. R., & Thompson, J. (2011). Parent and service providers' perceptions regarding the delivery of family-centred paediatric rehabilitation services in a children's hospital. *Child: Care, Health & Development, 37*(1): 64-73.

DLS. (2009). Assessments and services for disabled children: Disability Law Service UK.

Donabedien, A. (1988). The quality of care: how can it be assessed? *Journal of the American Medical Association, 260*(12): 1743-1748.

Douma, J. C. H., Dekker, M. C., & Koot, H. M. (2006). Supporting parents of youths with intellectual disabilities and psychopathology. *Journal of Intellectual Disability Research, 50*(Part 8): 570-581.

DSW. (2009a). "Garis Panduan Pendaftaran Orang Kurang Upaya": Department of Social Welfare, Malaysia.

DSW. (2009b). Statistic Report: Department of Social Welfare, Malaysia.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). The family support scales: reliability and validity. *Journal of Individual, Family and Community Wellness, 1*: 45-52.

Dusing, S. C., Skinner, A. C., & Mayer, M. L. (2004). Unmet need for therapy services, assistive devices, and related services: Data from the National Survey of Children With Special Health Care Needs. *Ambulatory Pediatrics, 4*(5): 448-454.

ESCAP. (2003). Biwako Millennium Framework for action towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific: Economic and Social Commission for Asia and the Pacific.

ESCAP. (2010). Disability at a glance 2010: A profile of 36 countries and areas in Asia and the Pacific: Economic and Social Commission for Asia and the Pacific.

Falkenbach, A. P., Drexsler, G., & Werler, V. (2008). The relation mother/child with disabilities: feelings and experiences. *Cien Saude Colet, 13 Suppl 2*: 2065-2073.

Farmer, J. E., Clark, M. J., Sherman, A., Marien, W. E., & Selva, T. J. (2005). Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics, 116*(3): 649-656.

Farmer, J. E., Marien, W. E., Clark, M. J., Sherman, A., & Selva, T. J. (2004). Primary care supports for children with chronic health conditions: Identifying and predicting unmet family needs. *Journal of Paediatric Psychology, 29*(5): 355 - 367.

Fereday, J., Oster, C., & Darbyshire, P. (2010). Partnership in practice: What parents of a disabled child want from a generic health professional in Australia. *Health and Social Care in the Community, 18*(6): 624-632.

Forsyth, R., McNally, R., James, P., Crossland, K., Woolley, M., & Colver, A. (2010). Variation at local government level in the support for families of severely disabled children and the factors that affect it. *Dev Med Child Neurol, 52*(11): e259-266.

Fournier, C. J., Davis, M. J., Patnaik, A., Elliott, T. R., Dyer, J. A., Jasek, E. E., & Phillips, C. D. (2010). Modeling caregivers' perceptions of children's need for formal care: Physical function, intellectual disability, and behavior. *Disability and Health Journal, 3*(3): 213-221.

Fulda, K. G., Lykens, K., Bae, S., & Singh, K. (2009). Factors for accessing a medical home vary among CSHCN from different levels of socioeconomic status. *Maternal & Child Health Journal 13*: 445-456.

Gaebler-Spira, D., & Desch, L. W. (2008). Prescribing assistive-technology systems: focus on children with impaired communication. *Pediatrics, 121*(6): 1271-1280.

Gannotti, M. E., Kaplan, L. C., Handwerker, W. P., & Groce, N. E. (2004). Cultural influences on health care use: Differences in perceived unmet needs and expectations of providers by Latino and Euro-American parents of children with special health care needs. *Journal of Developmental and Behavioral Pediatrics, 25*(3): 156-165.

Geere, J. L., Gona, J., Omondi, F. O., Kifalu, M. K., Newton, C. R., & Hartley, S. (2013). Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child: Care, Health And Development, 39*(3): 381-392.

Gelberg, L., Andersen, R. M., & Leake, B. D. (2000). The behavioural model for vulnerable populations: Application to medical care use and outcomes for homeless people. *Health Services Research, 34*(6): 1273 - 1302.

Ghandour, R. M., Perry, D. F., Kogan, M. D., & Strickland, B. B. (2010). The medical home as a mediator of the relation between mental health symptoms and family burden among children with special health care needs. *Academic Pediatrics, 11*(2): 161-169.

Gibson, B. E., Darrah, J., Cameron, D., Hashemi, G., Kingsnorth, S., Lepage, C., . . . Menna-Dack, D. (2009). Revisiting therapy assumptions in children's rehabilitation: Clinical and research implications. *Disability And Rehabilitation, 31*(17): 1446-1453.

Goddard, L., Davidson, P. M., Daly, J., & Mackey, S. (2008). People with an intellectual disability in the discourse of chronic and complex conditions: An invisible group? *Australian Health Review, 32*(3): 405-414.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2010). Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child: Care, Health and Development, 37*(2): 175 - 183.

Gordon, A., Lang, C., Larkin, R., & Johnston, L. M. (2012). Effect of social support services on the emotional well-being of caregivers of children with cerebral palsy. *Developmental Medicine and Child Neurology, 54*(s5): 62-63.

Greco, V., & Sloper, P. (2004). Care co-ordination and key worker schemes for disabled children: results of a UK wide survey. *Child: Care, Health and Development, 30*: 13 - 20.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64*(1): 150-163.

Hallberg, U., & Klingberg, G. (2005). Medical health care professionals' assessments of oral health needs in children with disabilities: A qualitative study. *European Journal of Oral Sciences, 113*(5): 363-368.

Hamamura, T., Heine, S. J., & Paulhus, D. L. (2008). Cultural differences in response styles: The role of dialectical thinking. *Personality and Individual Differences, 44*(4): 932 - 942.

Harrison, M. F., Able-Boone, H., & West, T. A. (2001). Facilitating inclusion in early childhood settings: Interdisciplinary preservice preparation. *Infant-Toddler Intervention, 11*(2): 129-141.

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development, 31*(2): 167-180.

Hendriks, A. H., Moor, J. M. D., Oud, J. H., & Franken, W. M. (2000). Service needs of parents with motor or multiply disabled children in Dutch therapeutic toddler classes. *Clinical Rehabilitation, 14*(5): 506-517.

Hennequin, M., Moysan, V., Jourdan, D., Dorin, M., & Nicolas, E. (2008). Inequalities in oral health for children with disabilities: A French national survey in special schools. *PLoS ONE, 3*(6).

Hornby, G., Murray, R., & Jones, R. (1987). Establishing a parent to parent service. *Child: Care, Health and Development, 13*(4): 277-286.

Houtrow A.J., Okumura M.J., Hilton J.F., & Rehm, R. S. (2011). Profiling health and health-related services for children with special health care needs with and without disabilities. *Academic Paediatrics, 11*(6): 508 - 516.

Houtrow, A. J., Okumura, M. J., & Rehm, R. S. (2010). Identifying health disparities and health care inequities between children with special health care needs with and without disabilities. *PM and R, 2*(9): S4.

Huang, I. C., Leite, W. L., Shearer, P., Seid, M., Revicki, D. A., & Shenkman, E. A. (2011). Differential item functioning in quality of life measure between children with and without special health-care needs. *Value in Health, 14*(6): 872-873.

Hung, J. W., Wu, Y. H., Chiang, Y. C., Wu, W. C., & Yeh, C. H. (2010). Mental health of parents having children with physical disabilities. *Chang Gung Med J, 33*(1): 82-91.

Inkelas, M., Raghavan, R., Larson, K., Kuo, A. A., & Ortega, A. N. (2007). Unmet mental health need and access to services for children with special health care needs and their families. *Ambulatory Pediatrics, 7*(6): 431-438.

Jackson, B., Finkler, D., & Robinson, C. (1995). A cost analysis of a case management system for infants with chronic illnesses and developmental disabilities. *Journal of Pediatric Nursing, 10*(5): 304-310.

Jackson, K. E., Krishnaswami, S., & McPheeters, M. (2011). Unmet health care needs in children with cerebral palsy: A cross-sectional study. *Research in Developmental Disabilities, 32*(6): 2714-2723.

Jansen, S. L., van der Putten, A. A., & Vlaskamp, C. (2013). What parents find important in the support of a child with profound intellectual and multiple disabilities. *Child: Care, Health And Development, 39*(3): 432-441.

Karaca-Mandic, P., Choi-Yoo, S. J., Lee, J., & Scal, P. (2014). Family out-of-pocket health care burden and children's unmet needs or delayed health care. *Academic Pediatrics, 14*(1): 101-108.

Kenney, M. K., & Kogan, M. D. (2011). Special needs children with speech and hearing difficulties: Prevalence and unmet needs. *Academic Pediatrics, 11*(2): 152-160.

Kertoy, M. K., Russell, D. J., Rosenbaum, P., Jaffer, S., Law, M., McCauley, D., & Gorter, J. W. (2012). Development of an outcome measurement system for service planning for children and youth with special needs. *Child: Care, Health and Development, 39*(5): 750-759.

King, G., Batorowicz, B., & Shepherd, T. A. (2008). Expertise in research-informed clinical decision making: Working effectively with families of children with little or no functional speech. *Evidence-Based Communication Assessment and Intervention, 2*(2): 106-116.

King, G., Cathers, T., King, S., & Rosenbaum, P. (2001). Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care, 30*(2): 111-134.

King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Paediatric Psychology, 24*(1): 41 - 53.

King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical and Occupational Therapy in Pediatrics, 22*(2): 53 - 77.

Klingberg, G., & Hallberg, U. (2012). Oral health - not a priority issue; a grounded theory analysis of barriers for young patients with disabilities to receive oral health care on the same premise as others. *European Journal of Oral Sciences, 120*: 232-238.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Paediatrics, 122*(1149): 1150 - 1158.

Kovanen, P. S. (2001). Comprehensiveness Is a cliche: professional practice in child assessment and planning. *Journal of Early Intervention, 24*(1): 25 - 34.

Kratz, L., Uding, N., Trahms, C. M., Villareale, N., & Kieckhefer, G. M. (2009). Managing childhood chronic illness: parent perspectives and implications for parent-provider relationships. *Families, Systems & Health, 27*(4): 303-313.

Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41*(5): 329 - 339.

Kuhlthau, K., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., . . . Perrin, J. M. (2005). Evidence for family-centered care for children with special health care needs: A systematic review. *Academic Pediatrics, 11*(2): 136-143.

Kuhlthau, K., Hill, K. S., Yucel, R., & Perrin, J. M. (2005). Financial burden for families of children with special health care needs. *Maternal and Child Health Journal, 9*(2): 207 - 218.

Lakhani, A., Gavino, I., & Yousafzai, A. (2013). The impact of caring for children with mental retardation on families as perceived by mothers in Karachi, Pakistan. *The Journal of the Pakistan Medical Association, 63*: 1468-1471.

Larkin, R., Marx, E., Gordon, A., & Johnston, L. M. (2012). The effect of respite services on the emotional well-being of caregivers of children with cerebral palsy. *Developmental Medicine and Child Neurology, 54*(s5): 63.

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development, 29*(5): 357 - 366.

Laws of Malaysia: Persons with Disabilities Act (2008).

Lewis, C. W. (2002). Dental care and children with special health care needs: A population-based perspective. *Academic Pediatrics, 9*(6): 420-426.

Lindeke, L. L., Leonard, B. J., Presler, B., & Garwick, A. (2002). Family-centered care coordination for children with special needs across multiple settings. *Journal of Pediatric Health Care, 16*(6): 290-297.

Lindsay, S. (2010). Perceptions of health care workers prescribing augmentative and alternative communication devices to children. *Disability and Rehabilitation: Assistive Technology, 5*(3): 209-222.

Liptak, G. S., Orlando, M., Yingling, J. T., Theurer-Kaufman, K. L., Malay, D. P., Tompkins, L. A., & Flynn, J. R. (2005). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care, 20*(4): 245-252.

Litt, J. S., & McCormick, M. C. (2015). Care coordination, the family-centered medical home, and functional disability among children with special health care needs. *Academic Pediatrics, 15*(2): 185-190.

Liza-Sharmini, A. T., Azlan, Z. N., & Zilfalil, B. A. (2006). Ocular findings in Malaysian children with Down syndrome. *Singapore Medical Journal, 47*(1): 14-19.

Long, T. M., & Perry, D. F. (2008). Pediatric physical therapists' perceptions of their training in assistive technology. *Physical Therapy, 88*(5): 629-639.

Lopez, J. M., Lewis, J. A., & Boldy, D. P. (2000). Evaluation of a Philippine community based rehabilitation programme. *Asia-Pacific Journal of Public Health, 12*(2): 85-89.

Loprest, P., & Davidoff, A. (2004). How children with special health care needs affect the employment decisions of low-income parents. *Maternal and Child Health Journal, 8*(3): 171-182.

Lysack, C., & Kaufert, J. (1994). Comparing the origins and ideologies of the independent movement and community based rehabilitation. *International Journal of Rehabilitation Research, 17*: 231 - 240.

Magnussen, H. J. (2011). *Childhood disability in rural Zambia: A qualitative study on the use of health care services.* (Doctoral thesis, University of Oslo). Retrieved from https://www.duo.uio.no/handle/10852/30039

Maldonado, G., & Greenland, S. (1993). Simulation study of confounder-selection strategies. *American Journal of Epidemiology, 138*(11): 923 - 936.

Maulik, P. K., & Darmstadt, G. L. (2007). Childhood disability in low- and middle-income countries: overview of screening, prevention, services, legislation, and epidemiology. *Pediatrics, 120* (Suppl 1): S1-55.

Mayer, M. L., Skinner, A. C., & Slifkin, R. T. (2004). Unmet need for routine and specialty care: Data from the National Survey of Children with Special Health Care Needs. *Paediatrics, 113*(2): e109.

McAdoo, H. P., Younge, S. N., Hughes, H. M., Hanshaw, C. W., & Murray, M. (2003). Use of coping resources among African American and Latino parents of children with special needs: implication for interventions. *Race and Society, 6*: 125 - 140.

McCarthy, J., & Boyd, J. (2002). Mental health services and young people with intellectual disability: Is it time to do better? *Journal of Intellectual Disability Research, 46*(3): 250-256.

McConachie, H., Huq, S., Munir, S., Kamrunnahar, Akhter, N., Ferdous, S., & Khan, N. Z. (2001). Difficulties for mothers in using an early intervention service for children with cerebral palsy in Bangladesh. *Child: Care, Health & Development, 27*(1): 1-12.

McConkey, R., Truesdale-Kennedy, M., Chang, M.-Y., Jarrah, S., & Shukri, R. (2006). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies, 45*: 65-74.

McIntosh, J., & Runciman, P. (2008). Exploring the role of partnership in the home care of children with special health needs: Qualitative findings from two service evaluations. *International Journal of Nursing Studies, 45*(5): 714-726.

McIntyre, S., Newland, J., Ison, N., Salmon, J., & Pearce, C. (2009). Community-based rehabilitation in Fiji: Evaluation of the competency, assessment, and local solutions (CAL) programme. *Developmental Medicine and Child Neurology, 51s2*(Abstracts of the Third International Cerebral Palsy Conference, 18-21 February 2009, Sydney, Australia), 77. doi: 10.1111/j.1469-8749.2008.03237.x

McPherson M., Arango P., Fox H., Lauver C., McManus M., Newacheck P.W., . . . B., S. (1998). A new definition of children with special health care needs. *Pediatrics, 102*: 137 - 140.

MOH. (2006). "Garispanduan pelaksanaan program penjagaan kanak-kanak berkeperluan khas di klinik kesihatan": Family Health Development Division, Department of Public Health, Ministry of Health Malaysia.

MOH. (2011). Ministry of Health Plan of Action: Health Care for Persons with Disabilities Years 2011 - 2020: Family Health Development Division, Department of Public Health, Ministry of Health Malaysia.

Mohd-Ali, B., Mohammed, Z., Norlaila, M., Mohd-Fadzil, N., Rohani, C. C., & Mohidin, N. (2006). Visual and binocular status of Down syndrome children in Malaysia. *Clinical & Experimental Optometry: Journal Of The Australian Optometrical Association, 89*(3): 150-154.

Mont, D. (2007). Measuring disability prevalence: Disability & Development Team, HDNSP, The World Bank.

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development, 33*(2): 180-187.

Nageswaran, S., & Farel, A. (2007). Access to a medical home for infants and young children with special healthcare needs. *Infants & Young Children, 20*(3): 222-228.

NECIC. (2012). Inclusive education as national policy for children with special needs: National Early Childhood Intervention Council Malaysia.

Nesbitt, R. C., Mackey, S., Kuper, H., Muhit, M., & Murthy, G. V. S. (2012). Predictors of referral uptake in children with disabilities in Bangladesh - exploring barriers as a first step to improving referral provision. *Disability And Rehabilitation, 34*(13): 1089-1095.

Newacheck, P. W., Inkelas, M., & Kim, S. E. (2004). Health services use and health care expenditures for children with disabilities. *Pediatrics, 114*(1): 79-85.

Nezu, S., Iwasaka, H., Saeki, K., Ishizuka, R., Goma, H., Okamoto, N., . . . Kurumatani, N. (2014). Reliability and validity of the Japanese version of the KIDSCREEN-52 health-related quality of life questionnaire for children/adolescents and parents/proxies. *Environmental Health and Preventive Medicine, 20*(1): 44-52.

Ngui, E. M., & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics, 117*: 1184-1196.

Ni Bhrolchain, C. M., Klein, L. E., & Smith, M. J. (1993). Children with disabilities and the Children Act: Who will assess their needs? *Public health, 107*(2): 101-106.

NIH. (2006a). The Third National Health and Morbidity Survey, Topic 6: Physical Disability (Vol. I, pp. 403-418): Institute for Public Health, National Institutes of Health, Ministry of Health Malaysia.

NIH. (2006b). The Third National Health and Morbidity Survey, Topic 16: Psychiatric Morbidity (Vol. II, pp. 453-468): Institute for Public Health, National Institutes of Health, Ministry of Health Malaysia.

Norizan, A., & Khadijah, S. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal Of Intellectual Disability Research, 54*(11): 992-1003.

Norlin, C., Sharp, A. L., & Firth, S. D. (2007). Unanswered questions prompted during pediatric primary care visits. *Ambulatory Pediatrics, 7*(5): 396-400.

Norwood Jr, K. W., & Slayton, R. L. (2013). Oral health care for children with developmental disabilities. *Pediatrics, 131*(3): 614-619.

O'Neil, M. E., Costigan, T. E., Gracely, E. J., & Wells, N. (2009). Parents' perspectives on access to rehabilitation services for their children with special healthcare needs. *Pediatric Physical Therapy, 21*(3): 254-260.

O'Neil, M. E., Ideishi, R. I., Nixon-Cave, K., & Kohrt, A. (2008). Care coordination between medical and early intervention services: Family and provider perspectives. *Families, Systems & Health, 26*(2): 119-134.

Ong, L. C., Afifah, I., Sofiah, A., & Lye, M. S. (1998). Parenting stress among mothers of Malaysian children with cerebral palsy: predictors of child- and parent-related stress. *Annals Of Tropical Paediatrics, 18*(4): 301-307.

Ong, L. C., Chandran, V., & Peng, R. (1999). Stress experienced by mothers of Malaysian children with mental retardation. *Journal Of Paediatrics And Child Health, 35*(4): 358-362.

Oredugba, F. A., & Sanu, O. O. (2006). Knowledge and behavior of Nigerian dentists concerning the treatment of children with special needs. *BMC Oral Health, 6*(9). doi: 10.1186/1472-6831-6-9

Parish, S. L., & Cloud, J. M. (2006). Financial well-being of young children with disabilities and their families. *Social Work, 51*(3): 223-232.

Parish, S. L., Rose, R. A., Dababnah, S., Yoo, J., & Cassiman, S. A. (2012). State-level income inequality and family burden of US families raising children with special health care needs. *Social Science & Medicine, 74*(3): 399-407.

Park, S.-Y., Glidden, L. M., & Shin, J. Y. (2009). Structural and functional aspects of social support for mothers of children with and without cognitive delays in Vietnam. *Journal of Applied Research in Intellectual Disabilities, 23*: 38 - 51.

Pastor, P. N., & Reuben, C. A. (2009). Emotional/behavioral difficulties and mental health service contacts of students in special education for non-mental health problems. *Journal of School Health, 79*(2): 82-89.

Pearlin, L. I. (1989). The sociological study of stress. *Journal of Health and Social Behaviour, 30*(3): 241-256.

Peduzzi, P., Concato, J., Kemper, E., Holford, T. R., & Feinstein, A. R. (1996). A simulation study of the number of events per variable in logistic regression analysis. *Journal of Clinical Epidemiology, 49*(12): 1373-1379.

Peredo, D. E., Davis, B. E., Norvell, D. C., & Kelly, P. C. (2010). Medical equipment use in children with disabilities: A descriptive survey. *Journal of Pediatric Rehabilitation Medicine, 3*(4): 259-267.

Perrin, E. C., Lewkowicz, C., & Young, M. H. (2000). Shared vision: Concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. *Pediatrics, 105*(Supplement 2): 277-285.

Perrin, J. M. (2002). Health services research for children wtih disabilities. *The Milbank Quarterly, 80*(2): 303 - 324.

Peter, E., Spalding, K., Kenny, N., Conrad, P., McKeever, P., & Macfarlane, A. (2007). Neither seen nor heard: Children and homecare policy in Canada. *Social Science and Medicine, 64*(8): 1624-1635.

Pongprapai, S., Tayakkanonta, K., Chongsuvivatwong, V., & Underwood, P. (1996). A study on disabled children in a rural community in southern Thailand. *Disability And Rehabilitation, 18*(1): 42-46.

Poon, K. K., Ooi, N., Bull, R., & Bailey Jr, D. B. (2014). Psychometric validation of the Family Outcome Survey-Revised in Singapore. *Research in Developmental Disabilities, 35*(7): 1534-1543.

Porterfield, S. L., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *American Journal of Public Health, 97*(2): 323 - 329.

Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: Evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics, 114*(4): e477-e482. doi: 10.1542/peds.2004-0240

Rahman, A. A., Mohamad, N., Imran, M. K., Ibrahim, W. P. W., Othman, A., Aziz, A. A., . . . van Rostenberghe, H. (2011). A preliminary study on the reliability of the Malay version of PedsQL Family Impact Module among caregivers of children with disabilities in Kelantan, Malaysia. *The Malaysian Journal of Medical Sciences, 18*(4): 63-68.

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., . . . Wood, E. (2004). Caregiving process and caregiver burden: conceptual models

to guide research and practice. *BMC Pediatrics, 4*:1. doi: 10.1186/1471-2431-4-1

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology, 55*(2): 139-150.

Ried, S., Strong, G., Wright, L., Wood, A., Goldman, A., & Bogen, D. (1995). Computers, assistive devices, and augmentative communication aids: Technology for social inclusion. *Journal of Head Trauma Rehabilitation, 10*(5): 80-90.

Roy, L., Roussea, J., Allard, H., Feldman, D., & Majnemer, A. (2008). Parental experience of home adaptation for children with motor disabilities. *Physical and Occupational Therapy in Pediatrics, 28*(4): 353-368.

Rupp, K., & Resslerb, S. (2009). Family caregiving and employment among parents of children with disabilities on SSI. *Journal of Vocational Rehabilitation, 30*(3): 153-175.

Saloojee, G., Phohole, M., Saloojee, H., & IJsselmuiden, C. (2007). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health & Development, 33*(3): 230-235.

Samuel, P. S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal Of Intellectual Disability Research, 56*(1): 1 - 16.

Satwant, S., Subramaniam, K. N., Prepageran, N., Raman, R., & Jalaludin, M. A. (2002). Otological disorders in Down's Syndrome. *The Medical Journal Of Malaysia, 57*(3): 278-282.

Schieve, L. A., Boulet, S. L., Kogan, M. D., Van Naarden-Braun, K., & Boyle, C. A. (2011). A population-based assessment of the health, functional status, and consequent family impact among children with Down syndrome. *Disability and Health Journal, 4*(2): 68-77.

Schmidt, S., Thyen, U., Chaplin, J., & Mueller-Godeffroy, E. (2007). Cross-cultural development of a child health care questionnaire on satisfaction, utilization, and needs. *Ambulatory Pediatrics, 7*(5): 374-382.

Schmidt, S., Thyen, U., Chaplin, J., Mueller-Godeffroy, E., & Bullinger, M. (2008). Healthcare needs and healthcare satisfaction from the perspective of parents of

children with chronic conditions: the DISABKIDS approach towards instrument development. *Child: Care, Health and Development, 34*(3): 355 - 366.

Sciberras, E., Iyer, S., Efron, D., & Green, J. (2010). Information needs of parents of children with attention-deficit/ hyperactivity disorder. *Clinical Pediatrics, 49*(2): 150-157.

Seid, M., Sobo, E. J., Gelhard, L. R., & Varni, J. W. (2004). Parents' reports of barriers to care for children with special health care needs: development and validation of the barriers to care questionnaire. *Ambulatory Pediatrics, 4*(4): 323-331.

Shandra, C. L., Avery, R. C., Hogan, D. P., & Msall, M. E. (2012). Child and adult disability in the 2000 Census: Disability is a household affair. *Disability and Health Journal, 5*(4): 241-248.

Siebes, R. C., Ketelaar, M., Gorter, J. W., Alsem, M., & Jongmans, M. J. (2012). Needs of families with children who have a physical disability: A literature review. *Critical Reviews in Physical and Rehabilitation Medicine, 24*(1-2), 85-108.

Simeonsson, R., Chen, J., & Hu, Y. (1995). Functional assessment of Chinese children with the ABILITIES index. *Disability and Rehabilitation, 17*(7): 400-410.

Simeonsson, R. J., & Bailey, D. B. (1991). The ABILITIES Index. Frank Porter Graham Child Development Center, University of North Carolina.

Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health And Development, 18*(5): 259-282.

SNZ. (2006). Disability Survey New Zealand: Child Content Questionnaire: Statistics New Zealand.

Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology, 29*(1): 113-132.

Suchman, E. A. (1965). Social patterns of illness and medical care. *Journal of Health and Human Behaviour, 6*: 2-16.

Sullivan, P. B., Juszczak, E., Lambert, B. R., Rose, M., Ford-Adams, M. E., & Johnson, A. (2002). Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. *Developmental Medicine and Child Neurology, 44*(7): 461-467.

Suriati, S., Zainiyah, S. S., Lye, M., & Norlijah, O. (2011). Assessing the unmet needs among caregivers of children with disabilities at the community-based rehabilitation centres in Selangor. *Malaysian Journal of Public Health Medicine, 11*(2): 32 - 40.

Swanson, M. E., Wall, S., Kisker, E., & Peterson, C. (2011). Health disparities in low-income families with infants and toddlers: needs and challenges related to disability. *Journal of Child Health Care, 15*(1): 25-38.

Tadema, A. C., & Vlaskamp, C. (2009). The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support. *British Journal of Learning Disabilities, 38*: 41 - 48.

Taylor, S., Wheeler, L. C., Taylor, J. R., & Griffin, H. C. (1996). Nutrition: an issue of concern for children with disabilities. *The Nurse Practitioner, 21*(10): 17-18, 20.

Thorburn, M. J., Desai, P., & Paul, T. J. (1992). Service needs of children with disabilities in Jamaica. *International Journal of Rehabilitation Research, 15*(1): 31-38.

Thyen, U., Sperner, J., Morfeld, M., Meyer, C., & Ravens-Sieberer, U. (2003). Unmet health care needs and impact on families with children with disabilities in Germany. *Ambulatory Pediatrics, 3*(2): 74-81.

Tracy, J., & Henderson, D. (2004). Children and adolescents with developmental disabilities. The GP's role. *Australian family physician, 33*(8): 591-597.

Tsai, W.-C., Kung, P.-T., & Wang, J.-Y. (2012). Disparities in the use of preventive health care among children with disabilities in Taiwan. *Research in Developmental Disabilities, 33*(2): 324-333.

Ueda, K., Bailey Jr, D. B., Yonemoto, N., Kajikawa, K., Nishigami, Y., Narisawa, S., . . . Kodama, K. (2013). Validity and reliability of the Japanese version of the Family Needs Survey. *Research in Developmental Disabilities, 34*(10): 3596-3606.

UN. (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol: United Nations.

UNICEF. (2014). Children with disabilities in Malaysia: Mapping the policies, programmes, interventions and stakeholders: Unicef Malaysia.

van Dyck, P. C., Kogan, M. D., McPherson, M. G., Weissman, G. R., & Newacheck, P. W. (2004). Prevalence and characteristics of children with special health care needs. *Archives of Paediatric and Adolescent Medicine, 158*: 884 - 891.

Van Horn, M. L., Bellis, J. M., & Snyder, S. W. (2001). Family Resource Scale-Revised: Psychometrics and validation of a measure of family resources in a sample of low-income families. *Journal of Psychoeducational Assessment, 19*(1): 54-68.

Varni, J. W., Sherman, S. A., Burwinkle, T. M., Dickinson, P. E., & Dixon, P. (2004). The PedsQL Family Impact Module: Preliminary reliability and validity. *Health & Quality of Life Outcomes, 2*: 55-56.

Wan, T. T. H., & Odell, B. G. (1981). Factors affecting the use of social and health services among the elderly. *Ageing and Society, 1*(1): 95-115.

Warfield, M. E., & Gulley, S. (2006). Unmet need and problems accessing specialty medical and related services among children with special health care needs. *Maternal and Child Health Journal, 10*(2): 201-216.

Warfield, M. E., Krauss, M. W., Hauser-Cram, P., Upshur, C. C., & Shonkoff, J. P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Journal of Developmental and Behavioral Pediatrics, 20*(1): 9-16.

Washington, K., & Schwartz, I. S. (1996). Maternal perceptions of the effects of physical and occupational therapy services on caregiving competency. *Physical and Occupational Therapy in Pediatrics, 16*(3): 33-54.

Wei, X., & Yu, J. W. (2012). The concurrent and longitudinal effects of child disability types and health on family experiences. *Maternal and Child Health Journal, 16*(1): 100-108.

Westling, D. L. (1997). What parents of young children with mental disabilities want: The views of one community. *Focus on Autism & Other Developmental Disabilities, 12*(2): 67.

Wharton, S., Hames, A., & Milner, H. (2005). The accessibility of general NHS services for children with disabilities. *Child: Care, Health and Development, 31*(3): 275-282.

Whitehead, M. (1991). The concepts and principles of equity and health. *Health Promotion International, 6*(3): 217 - 228.

WHO. (2001). International Classification of Functioning, Disability and Health: World Health Organization.

WHO. (2011). World Report on Disability: World Health Organization, The World Bank.

WHO/ESCAP. (2008). Chapter 3: Data collection methods and instruments *Training Manual on Disability Statistics*.

Wijesinghe, C. J., Cunningham, N., Fonseka, P., Hewage, C. G., & Østbye, T. (2015). Factors associated with caregiver burden among caregivers of children with cerebral palsy in Sri Lanka. *Asia-Pacific Journal of Public Health, 27*(1): 85-95.

Witt, W. P., Kasper, J. D., & Riley, A. W. (2003). Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination. *Health Serv Res, 38*(6 Pt 1): 1441-1466.

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it from being helpful? *Journal of Intellectual Disability Research, 53*(7): 644-653.

Woodhouse, J. M. (1998). Investigating and managing the child with special needs. *Ophthalmic and Physiological Optics, 18*(2): 147-152.

Wright, J., Williams, R., & Wilkinson, J. R. (1998). Development and importance of health needs assessment. *British Medical Journal, 316*(7140): 1310 - 1313.

Xiong, N., Yang, L., Yu, Y., Hou, J., Li, J., Li, Y., . . . Jiao, Z. (2011). Investigation of raising burden of children with autism, physical disability and mental disability in China. *Research in Developmental Disabilities, 32*(1): 306-311.

Xu, K., Evans, D. B., Kawabata, K., Zeramdini, R., Klavus, J., & Murray, C. J. L. (2003). Household catastrophic health expenditure: A multicountry analysis. *Lancet, 362*: 111 - 117

Yu, S. M., Nyman, R. M., Kogan, M. D., Huang, Z. J., & Schwalberg, R. H. (2004). Parent's language of interview and access to care for children with special health care needs. *Ambulatory Pediatrics, 4*(2): 181-187.

Zuckerman, K. E., Lindly, O. J., Bethell, C. D., & Kuhlthau, K. (2014). Family impacts among children with autism spectrum disorder: the role of health care quality. *Academic Pediatrics, 14*(4): 398-407.

## LIST OF PUBLICATIONS AND PAPERS PRESENTED

PUBLICATIONS

1. Tan S.H. (2015). Unmet health care service needs of children with disabilities in Penang, Malaysia. *Asia Pacific Journal of Public Health, 27*(s8), 41S-51S.

2. Tan S.H. (2015). Development and psychometric properties of a scale assessing the needs of caregivers of children with disabilities. *Disability and Health Journal, 8*(3), 414-423.

3. Tan S.H. (2016). Assessing the needs of caregivers of children with disabilities in Penang, Malaysia. *Health and Social Care in the Community*, doi: 10.1111/hsc.12325.

ORAL AND POSTER PRESENTATIONS

1. Unmet health care service needs of children with disabilities in Penang, Malaysia. Oral presentation, *Asia Pacific Academic Consortium of Public Health Conference*, Kuala Lumpur, Oct 2014.

2. Assessing the needs of caregivers of children with disabilities in Penang, Malaysia. Poster, *Asian Society of Paediatric Research (ASPR) Conference*, Osaka, April 2015.

3. Unmet service needs of children with learning and multiple disabilities in Penang, Malaysia: A descriptive analysis". Poster, *ASPR Conference*, Osaka, April 2015.

4. Financial impact on families caring for a child with disability: A cross-sectional study in Penang, Malaysia. Poster, *11th Ministry of Health-Academy of Medicine Malaysia (MOH-AMM) Scientific Meeting*, Kuala Lumpur, Aug 2015.

5. Caring for a child with disability: How supportive are we? Poster, *11th MOH-AMM Scientific Meeting*, Kuala Lumpur, Aug 2015.

**APPENDIX A**

RESEARCH QUESTIONNAIRE FORM


Department of Social and Preventive Medicine

UNIVERSITY MALAYA

CODE NO. | | | |

DATE: _____

# UNMET NEEDS OF CHILDREN WITH DISABILITIES AND THEIR CAREGIVERS IN PENANG, NORTHERN MALAYSIA

Instructions to all respondents:

- This survey is about the needs and difficulties getting access to services for children with disabilities and their families. The information you give will be used to help improve and plan services for them.
- This questionnaire should be answered by the parents of the child with disability (or other primary caregiver if the parents are not available).
- The answer you give will be kept confidential.
- Completing the survey is voluntary. Whether or not you answer the questions will not affect the current management of the child.
- Please read and attempt to answer all questions. Please answer the questions truthfully.
- **Please return the completed form by post using the addressed envelope provided.**

*Thank you very much for your co-operation*

For sections 1 – 7, please circle the number for the corresponding answer.

| | | |
|---|---|---|
| 1 | **PRIMARY CAREGIVER'S INFORMATION** | |
| 1.1 | What is your age? | _____ years |
| 1.2 | What is your ethnicity? | 1 Malay<br>2 Chinese<br>3 Indian<br>4 Others |
| 1.3 | What is your highest education level? | 1 No education<br>2 Primary<br>3 Lower secondary (Form 1 – 3)<br>4 Upper secondary (Form 4 – 6)<br>5 Tertiary (higher than secondary education) |
| 1.4 | What is your occupation? | _____ |
| 1.5 | What is your marital status?<br><br>*(IF MARRIED, PLEASE ANSWER QUESTIONS 1.6 AND 1.7)* | 1 Single<br>2 Married<br>3 Widowed<br>4 Separated/divorced |
| 1.6 | What is your husband/wife's highest education level? | 1 No education<br>2 Primary<br>3 Lower secondary<br>4 Upper secondary<br>5 Tertiary |
| 1.7 | What is your husband/wife's occupation? | _____ |
| 1.8 | How many children do you have? | _____ |
| 1.9 | How many of them have disabilities/special needs? | _____ |
| 1.10 | Do you have any medical illness? | 1 Yes<br>2 No |
| | Please specify what medical illness. | _____ |

| | | |
|---|---|---|
| 1.11 | Does your husband/wife have any medical illness?<br><br>Please specify what medical illness. | 1 Yes<br>2 No<br><br>_____ |
| 2 | **CHILD'S INFORMATION** | |
| 2.1 | Is your child bedridden? | 1 Yes<br>2 No |
| 2.2 | Does your child have an OKU card? | 1 Yes<br>2 No |
| 2.3 | How would you rate your child's severity of disability?<br>(Think of how much or how often your child's disability affects his/her ability to do things other children his/her age do) | 1 2 3 4 5<br>Mild → Moderate →Severe |
| 2.4 | From what you have been told, or what you know, how did the disability occur? | 1 Born with the condition (congenital)<br>2 Due to birth complication (eg. birth asphyxia, infection at birth, prematurity)<br>3 Due to a childhood illness<br>4 Due to an accident<br>5 Others, specify<br>_____<br>6 Don't know |
| 3 | **INCOME** | |
| 3.1 | *What is your average household income per month?* | |
| 3.1.1 | Income from your work/salary | RM _____ |
| 3.1.2 | Money from the Social Welfare Department | RM _____ |
| 3.1.3 | Income from other sources (eg. from relatives, welfare organizations, NGOs) | RM _____ |

| | | |
|---|---|---|
| 4 | **CARE EXPENDITURE** | |
| 4.1 | *In the **past one year**, how much did you spend using your own money/out of pocket to pay for your disabled/special needs child's care*? | Expenditure for disabled/special needs child in the PAST YEAR |
| 4.1.1 | Doctor's visits | RM _____/year |
| 4.1.2 | Hospitalization (including expenses borne by caregivers for that admission) | RM _____/year |
| 4.1.3 | Medicine prescribed by doctors | RM _____/year |
| 4.1.4 | Complementary medicine (eg. supplements, herbal medicine) | RM _____/year |
| 4.1.5 | Medical supplies/equipment | RM_____/year |
| 4.1.6 | Dental services | RM _____/year |
| 4.1.7 | Other allied health services (physiotherapy/occupational therapy/speech therapy/psychologist/dietitian) | RM _____/year |
| 4.1.8 | Transportation to medical/therapy appointments (petrol money, bus fare) | RM _____/year |
| 4.1.9 | Payment to others to take care of child (specially employed maid, babysitter, nursery) | RM _____/year |
| 4.1.10 | Alternative treatment (eg. homeopathy, massage, music therapy etc.) | RM _____/year |
| 4.1.11 | Education fees (kindergarten, school, special classes organized by NGOs) | RM _____/year |
| 4.1.12 | Other care related expenses | RM _____/year |
| | Please specify (eg.special milk formula, diapers) | _____<br>_____ |
| 4.2 | **To what extent are these expenses causing financial problems?** | 1 Not a problem<br>2 Small problem<br>3 Big problem |

| | | |
|---|---|---|
| 5 | **EMPLOYMENT** | |
| 5.1 | Has attending to your child's needs caused employment problems to you or your husband/wife such as: | |
| 5.1.1 | Having to stop work | 1 Yes<br>2 No |
| 5.1.2 | Taking too many days of leave | 1 Yes<br>2 No |
| 5.2 | Do you or your spouse have problems taking time off work to attend to your child's needs? | 1 Not a problem<br>2 Small problem<br>3 Big problem |
| 6 | **SOCIAL SUPPORT** | |
| 6.1 | Do you have someone to help you in the day to day care of your child (besides your husband/wife)? | 1 Yes<br>2 No |
| 6.2 | If yes, who is it?<br>(You may circle more than one answer) | 1 Child's siblings<br>2 Child's grandparents<br>3 Other relatives<br>4 Maid<br>5 Babysitter<br>6 Others, please specify<br><br>_____ |
| 6.3 | Did you join any support group/organization/society related to your child's disability? | 1 Yes<br>2 No |
| 6.4 | If no, what are the reasons for not joining?<br>(eg. not needed, no time, do not know of such organizations available, do not think it will benefit you or your child) | _____<br><br>_____ |

| | | |
|---|---|---|
| 7 | **<u>EDUCATION FOR CHILD</u>** | |
| 7.1 | *If child is 0 – 3 years old:*<br>Do you know/ Have you heard about "early intervention"? | 1 Yes<br>2 No |
| 7.2 | *If child is 4 – 6 years old:*<br>Do you have problems finding a pre-school program/kindergarten for your child? | 1 Not a problem<br>2 Small problem<br>3 Big problem<br>4 Not applicable<br>(eg. child has severe learning disability) |
| 7.3 | *If child is 7 – 18 years old:*<br>Do you have problems finding a suitable school for your child? | 1 Not a problem<br>2 Small problem<br>3 Big problem<br>4 Not applicable<br>(eg. child has severe learning disability) |
| 7.4 | Please explain the problems you face.<br>(eg. lack of facilities for the physically disabled in schools, lack of special education teachers specific to your child's disability,<br>do not know what type of education is suitable for your child,<br>do not know what are the types of special schools or classes available in your area)<br><br>_____<br><br>_____<br><br>_____ | |

For sections 8 and 9, please tick (√) the column with the most appropriate answer.

**8. REHABILITATION SERVICES**

How frequent did your child receive early intervention program or rehabilitation services (physiotherapy/ occupational therapy) at the following places in the **past one year**?

| | Not relevant | Did not receive or very infrequent | Once every 4 - 6 months | Once every 2 - 3 months | Once a month | ≥ twice a month |
|---|---|---|---|---|---|---|
| Physiotherapy at government hospital | | | | | | |
| Occupational therapy at government hospital | | | | | | |
| Physiotherapy or occupational therapy at government clinic | | | | | | |
| Community rehabilitation centre run by Social Welfare Department *"Pusat pemulihan dalam Komuniti"* (PDK) | | | | | | |
| Physiotherapy or occupational therapy at Private hospital/EIP centre/therapist | | | | | | |
| NGO centre/ voluntary organization | | | | | | |
| Home visit by Public Health Nurse | | | | | | |
| Home visit by PDK worker | | | | | | |

**9. NEED FOR HEALTH SERVICES AND ASSISTIVE DEVICES**

In your opinion, in the **past one year**, did your child need these services/assistive devices?

| | Yes | No | Don't know |
|---|---|---|---|
| Specialist doctor | | | |
| Physiotherapy | | | |
| Occupational therapy | | | |
| Speech therapy | | | |
| Mental health/ psychology services | | | |
| Dental services | | | |
| Vision related services | | | |
| Hearing related services | | | |
| Home nursing care (eg. suctioning, changing feeding tubes) | | | |
| Nutritional/feeding advice | | | |
| Mobility aids (eg. wheelchair, crutches) | | | |
| Vision aids (eg. spectacles) | | | |
| Hearing aids | | | |
| Communication aids (eg. flash cards, computer programs) | | | |
| Disposable items (eg. suction catheters, needles, syringes) | | | |
| Medical equipment (eg. portable ventilator, suction machine) | | | |
| Modifications to the home (eg. widened doorways, hand rails) | | | |

If the services/ assistive devices were needed, did your child receive them?

| | **Yes** (Received fully/ all the time) | **No** (Did not receive at all) | **Sometimes** (Received partly) | **No need** |
|---|---|---|---|---|
| Specialist doctor | | | | |
| Physiotherapy | | | | |
| Occupational therapy | | | | |
| Speech therapy | | | | |
| Mental health/ psychology services | | | | |
| Dental services | | | | |
| Vision related services | | | | |
| Hearing related services | | | | |
| Home nursing care (eg. suctioning, changing feeding tubes) | | | | |
| Nutritional advice | | | | |
| Mobility aids (eg. wheelchair, crutches) | | | | |
| Vision aids (eg. spectacles) | | | | |
| Hearing aids | | | | |
| Communication aids (eg. flash cards, computer programs) | | | | |
| Disposable items (eg. suction catheters, needles, syringes) | | | | |
| Medical equipment (eg. portable ventilator, suction machine) | | | | |
| Modifications to the home (eg. widened doorways, hand rails) | | | | |

**10 BARRIERS TO CARE**

Did your child not receive those services/ assistive devices due to the following reasons?

| | Yes | No |
|---|---|---|
| Could not afford cost of services | | |
| Could not afford cost of assistive devices | | |
| No transport | | |
| Could not afford cost of transport | | |
| Noone to send | | |
| Place of rehabilitation/ therapy too far from home | | |
| Did not know where to go for rehabilitation/ therapy | | |
| Did not know where to go to get assistive devices | | |
| Appointment date too far | | |
| Number of rehabilitation/therapy sessions inadequate | | |
| Poor communication with service provider<br>(eg. using different language) | | |
| Service provider's skills are inadequate | | |
| Equipment at rehabilitation place inadequate | | |
| Previously badly treated | | |
| Could not take time off work or had other commitments | | |

Other reasons, please state:

_____

_____

_____

| | | |
|---|---|---|
| **11** | **CAREGIVER NEEDS**<br><br>Please circle your answers according to how much help is currently needed. | 1 Help not at all needed<br>2 Help rarely needed<br>3 Help sometimes needed<br>4 Help very much needed<br>5 Help extremely needed |
| 11.1 | **<u>Community services</u>**<br><br>*I need help finding the following for my child:* | |
| 11.1.1 | Transportation to medical appointments | 1 2 3 4 5 |
| 11.1.2 | Finding a trained person for daycare | 1 2 3 4 5 |
| 11.1.3 | Finding a trained person to take care of my child for a few days when my spouse and I need to get away | 1 2 3 4 5 |
| 11.1.4 | Education which is suitable for my child (school, early intervention program, therapy) | 1 2 3 4 5 |
| 11.1.5 | Social or recreational activities for my child | 1 2 3 4 5 |
| 11.1.6 | Care coordination (making sure my child gets all the services he/she needs) | 1 2 3 4 5 |
| 11.2 | **Information needs**<br><br>*I need help obtaining **more information** on:* | |
| 11.2.1 | My child's condition or disability | 1 2 3 4 5 |
| 11.2.2 | Current services available for my child | 1 2 3 4 5 |
| 11.2.3 | Future services available for my child | 1 2 3 4 5 |
| 11.2.4 | How to integrate therapy into daily activities | 1 2 3 4 5 |
| 11.2.5 | How to handle my child's behaviour | 1 2 3 4 5 |
| 11.2.6 | How to play with or talk to my child | 1 2 3 4 5 |

| | | |
|---|---|---|
| 11.3 | **Support needs**<br><br>*I need help getting support such as:* | |
| 11.3.1 | Having a family member/friend/counselor to talk to about problems | 1 2 3 4 5 |
| 11.3.2 | Learning stress management techniques | 1 2 3 4 5 |
| 11.3.3 | Having more opportunities to meet and talk with other parents of disabled children | 1 2 3 4 5 |
| 11.3.4 | Having more time for myself | 1 2 3 4 5 |
| 11.4 | **Financial needs**<br><br>*I need more **help in paying** for:* | |
| 11.4.1 | Daily expenses such as food, clothing and transportation | 1 2 3 4 5 |
| 11.4.2 | Educational or therapy services | 1 2 3 4 5 |
| 11.4.3 | Special equipment/toys my child needs | 1 2 3 4 5 |
| 11.4.4 | Child care | 1 2 3 4 5 |

Other comments (not compulsory):

You can elaborate on:

1) Any other problems faced in your experience of taking care of your child
2) How care for your child can be improved

_____

_____

_____

FAMILY SUPPORT SCALE (Adapted from Hanley, Tasse, Aman and Pace, 1998)

This is a list of people and groups that often are helpful to members of a family raising a young child. Please describe **how helpful these sources have been to your family** during the **past 3 to 6 months**. If a source of help has not been available to your family during this period of time (for example if your parents have passed away), please circle the "not available" response.

| | Not available | Not at all helpful | Sometimes helpful | Generally helpful | Very helpful | Extremely helpful |
|---|---|---|---|---|---|---|
| 1 Your parents | 0 | 1 | 2 | 3 | 4 | 5 |
| 2 Your spouse or partner's parents | 0 | 1 | 2 | 3 | 4 | 5 |
| 3 Your relatives (other than parents) | 0 | 1 | 2 | 3 | 4 | 5 |
| 4 Your spouse or partner's relatives | 0 | 1 | 2 | 3 | 4 | 5 |
| 5 Spouse or partner | 0 | 1 | 2 | 3 | 4 | 5 |
| 6 Friends | 0 | 1 | 2 | 3 | 4 | 5 |
| 7 Your own children | 0 | 1 | 2 | 3 | 4 | 5 |
| 8 Co-workers | 0 | 1 | 2 | 3 | 4 | 5 |
| 9 Parents of other children with special needs | 0 | 1 | 2 | 3 | 4 | 5 |
| 10 Health care workers eg. doctor, nurse, therapist | 0 | 1 | 2 | 3 | 4 | 5 |
| 11 School/ PDK/ day care centre | 0 | 1 | 2 | 3 | 4 | 5 |
| 12 Social welfare department/ officer | 0 | 1 | 2 | 3 | 4 | 5 |
| 13 Education department/ officer | 0 | 1 | 2 | 3 | 4 | 5 |
| 14 Voluntary organizations/ NGO | 0 | 1 | 2 | 3 | 4 | 5 |

## **ABILITIES Index** (Adapted from Simeonsson & Bailey, 1991)

**INSTRUCTION**: *In each column, circle the number that best rates your child.*

Ratings in each column are made on a scale of 1 to 6, with 1 indicating normal ability, 2 (suspected) indicating some questions about the child's ability, and 6 indicating extreme or profound lack of ability. In making each rating, think about your child compared to other children the same age. The guidelines below are provided to assist you in making each rating.

| | | |
|---|---|---|
| **Audition (Hearing)**<br>Think about the child's ability to hear in everyday activities. Score hearing for each ear separately. A score of 6 (Profound loss) means that the child has no hearing. Rate the child's hearing without a hearing aid. | **Behaviour & Social Skills**<br>Two ratings are made in this area, one for social skills and one for inappropriate or unusual behaviour. Social skills refer to the child's ability to relate to others in a meaningful manner. Inappropriate & unusual behaviour may include fighting, hitting, screaming, rocking, hand flapping, biting self, etc… | **Intellectual Function (Thinking & Reasoning)**<br>This rating reflects the child's abilities to think and reason. Think about the way the child solves problems and plays with toys and compare this to other children of the same age. |
| **Limbs (Use of Hands, Arms & Legs)**<br>Think about the child's ability to use his or her hands, arms, and legs in daily activities. Score left and right limbs separately. A score of 6 (Profound difficulty) means that the child has no use of a limb. | **Intentional Communication (Understanding & Communicating with others)**<br>Two ratings are made, one for the child's ability to understand others and one for the child's ability to communicate in ways other than talking (signs, gestures, picture boards). Think about the child's ability to understand and communicate with others and compare this to other children of the same age. | **Tonicity (Muscle Tone)**<br>Think about the child's muscle tone. Normal means that the child's muscle tone is not in the neither tight nor loose. If the child's muscle tone is not in the normal range, place an "X" in each box that indicates the degree of tightness or looseness or both. Two ratings should be made since, in some children, tight ness or looseness can vary in different parts of the body or from one time to the next. |
| **Integrity of Physical Health (Overall Health)**<br>Think about the child's general health. Normal means the usual health problems & illnesses typical for a child this age. If there is a health problem, ratings should be made indicating the degree to which health problems limit activities. Ongoing health problems may include seizures, diabetes, muscular dystrophy, cancer, etc. | **Eyes (Vision)**<br>Think about the child's ability to see in everyday activities. Score both the left & right eye. A score of 6 (Profound loss) means that the child has no vision. Rate the child's vision without glasses. | **Structural Status (Shape, Body Form & Structure)**<br>This rating reflects the form and structure of the child's body. Normal means that there are no differences associated with form, shape, or structure of the body parts. Differences in form include conditions like cleft palate or club foot; differences in structure include conditions like curved spine and arm or leg deformity. Ratings should indicate how much these differences interfere with how the child moves, plays, or looks. |

| | | **Normal** | **Suspected** disability/ difficulty | **Mild** disability/ difficulty | **Moderate** disability/ difficulty | **Severe** disability/ difficulty | **Profound** or extreme disability/ difficulty |
|---|---|---|---|---|---|---|---|
| **A**udition (Hearing) | Left ear | 1 | 2 | 3 | 4 | 5 | 6 |
| | Right ear | 1 | 2 | 3 | 4 | 5 | 6 |
| **B**ehaviour and social skills | Social skills | 1 | 2 | 3 | 4 | 5 | 6 |
| | Inappropriate behaviour | 1 | 2 | 3 | 4 | 5 | 6 |
| **I**ntellectual functioning | Thinking and reasoning | 1 | 2 | 3 | 4 | 5 | 6 |
| **L**imbs (Use of hands, arms and legs) | Right hand | 1 | 2 | 3 | 4 | 5 | 6 |
| | Right arm | 1 | 2 | 3 | 4 | 5 | 6 |
| | Right leg | 1 | 2 | 3 | 4 | 5 | 6 |
| | Left hand | 1 | 2 | 3 | 4 | 5 | 6 |
| | Left arm | 1 | 2 | 3 | 4 | 5 | 6 |
| | Left leg | 1 | 2 | 3 | 4 | 5 | 6 |
| **I**ntentional communication | Understanding others | 1 | 2 | 3 | 4 | 5 | 6 |
| | Communicating with others | 1 | 2 | 3 | 4 | 5 | 6 |
| **T**onicity (Muscle tone) | Degree of tightness | 1 | 2 | 3 | 4 | 5 | 6 |
| | Degree of looseness | 1 | 2 | 3 | 4 | 5 | 6 |
| **I**ntegrity of physical health | Overall health | 1 | 2 | 3 | 4 | 5 | 6 |
| **E**yes (Vision) | Left eye | 1 | 2 | 3 | 4 | 5 | 6 |
| | Right eye | 1 | 2 | 3 | 4 | 5 | 6 |
| **S**tructural status | Shape, Body Form & Structure | 1 | 2 | 3 | 4 | 5 | 6 |

**APPENDIX B**

UNIVERSITI MALAYA

PUSAT PERUBATAN UM

**MEDICAL ETHICS COMMITTEE**
**UNIVERSITY MALAYA MEDICAL CENTRE**
ADDRESS: LEMBAH PANTAI, 59100 KUALA LUMPUR, MALAYSIA
TELEPHONE: 03-79493209 / 2251 FAXIMILE: 03-79492030

| | |
|---|---|
| **NAME OF ETHICS COMMITTEE/IRB:**<br>Medical Ethics Committee, University Malaya Medical Centre<br><br>**ADDRESS:** LEMBAH PANTAI<br>59100 KUALA LUMPUR | **ETHICS COMMITTEE/IRB REFERENCE NUMBER:**<br><br>950.2 |
| **PROTOCOL NO (if applicable):**<br><br>**TITLE:** Unmet needs of children with disabilities and their caregivers in Penang, Nothern Malaysia | **VERSION NO.:** |
| **PRINCIPAL INVESTIGATOR:** Dr. Tan Seok Hong | **SPONSOR:** |

The following item [✓] have been received and reviewed in connection with the above study to be conducted by the above investigator.

| | |
|---|---|
| [✓] Application to Conduct Research Project (form) | Ver date: 28 Sep 12 |
| [✓] Study Protocol | Ver date: |
| [ ] Investigator Brochure | Ver date: |
| [✓] Patient Information Sheet | Ver date: |
| [✓] Consent Form | Ver date: |
| [✓] Questionnaire | Ver date: |
| [✓] Investigator's CV (Dr. Tan Seok Hong) | Ver date: |

and the decision is [✓] :

[✓] Approved
[ ] Modification requested (item specified below or in accompanying letter)
[ ] Rejected (reasons specified below or in accompanying letter)

Comments:

*Investigator are required to:*

1) *follow instructions, guidelines and requirements of the Medical Ethics Committee.*
2) *report any protocol deviations/violations to Medical Ethics Committee.*
3) *provide annual and closure reports to the Medical Ethics Committee.*
4) *comply with International Conference on Harmonization – Guidelines for Good Clinical Practice (ICH-GCP) and the Declaration of Helsinki.*
5) *obtain permission from the Director of UMMC before starting research that involves recruitment of UMMC patients.*
6) *ensure that if the research is sponsored, the usage of consumable items and laboratory tests from UMMC services are not charged in the patient's hospital bills but are borne by the research grant.*
7) *note that he/she can appeal to the Chairman of MEC for studies that are rejected.*
8) *note that Medical Ethics Committee may audit the approved study.*
9) *ensure that the study does not take precedence over the safety of subjects.*

Date of meeting:
Date of approval: 05 OCTOBER 2012

c.c Head
Department of Social & Preventive Medicine

Deputy Dean (Research)
Faculty of Medicine

Secretary
Medical Ethics Committee
University Malaya Medical Centre

.....
**PROF. DATUK LOOI LAI MENG**
Chairman
Medical Ethics Committee

**PEJABAT TIMBALAN KETUA PENGARAH KESIHATAN**
***OFFICE OF THE DEPUTY DIRECTOR-GENERAL OF HEALTH***
**(PENYELIDIKAN & SOKONGAN TEKNIKAL)**
***(RESEARCH & TECHNICAL SUPPORT)***
**KEMENTERIAN KESIHATAN MALAYSIA**
***MINISTRY OF HEALTH MALAYSIA***
Aras 12, Blok E7, Parsel E, Presint 1
*Level 12, Block E7, Parcel E, Precint 1*
Pusat Pentadbiran Kerajaan Persekutuan
*Federal Government Administrative Centre*
62590 PUTRAJAYA

Tel. : 03-88832543
Faks : 03-88895184

**JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN**
**KEMENTERIAN KESIHATAN MALAYSIA**
**d/a Institut Pengurusan Kesihatan**
**Jalan Rumah Sakit, Bangsar**
**59000 Kuala Lumpur**

Ruj. Kami : (2) dlm.KKM/NIHSEC/08/0804/P12-975
Tarikh : 21 Disember 2012

Dr. Tan Seok Hong
Fakulti Perubatan
Universiti Malaya

Puan,

**NMRR-12-1055-13635**
**UNMET NEEDS OF CHILDREN WITH DISABILITIES AND THEIR CAREGIVERS IN PENANG**

**Lokasi Projek : Komuniti-komuniti di Pulau Pinang**

Dengan hormatnya perkara di atas adalah dirujuk.

2. Jawatankuasa Etika & Penyelidikan Perubatan (JEPP), Kementerian Kesihatan Malaysia (KKM) mengambil maklum bahawa projek tersebut adalah untuk memenuhi keperluan akademik Program Sarjana Kedoktoran Kesihatan Awam (DrPH), Universiti Malaya (UM).

3. Sehubungan dengan ini, dimaklumkan bahawa pihak JEPP KKM tiada halangan, dari segi etika, ke atas pelaksanaan projek tersebut. JEPP mengambil maklum bahawa kajian ini tidak melibatkan sebarang intervensi dan hanya menggunakan borang soalselidik dan temuramah sahaja untuk mengumpul data kajian. Segala rekod dan data adalah SULIT dan hanya digunakan untuk tujuan kajian dan semua isu serta prosedur mengenai *data confidentiality* mesti dipatuhi. Kebenaran daripada Pengarah Kesihatan Negeri di mana kajian akan dijalankan mesti diperolehi terlebih dahulu sebelum kajian dijalankan. Puan perlu akur dan mematuhi keputusan tersebut.

4. Adalah dimaklumkan bahawa kelulusan ini adalah selama setahun dan Puan perlu menghantar *'Continuing Review Form'* setiap tahun bagi memperbaharui kelulusan etika. Laporan tamat kajian dan sebarang penerbitan dari kajian ini hendaklah dikemukakan kepada Jawatankuasa Etika & Penyelidikan Perubatan selepas tamatnya kajian ini.

Sekian terima kasih.

**BERKHIDMAT UNTUK NEGARA**

Saya yang menurut perintah,

**(DATO' DR CHANG KIAN MENG)**
Pengerusi
Jawatankuasa Etika & Penyelidikan Perubatan
Kementerian Kesihatan Malaysia

**APPENDIX C**

ELSEVIER

Disability and Health Journal 8 (2015) 414–423

Disability and Health Journal

www.disabilityandhealthjnl.com

Research Paper

# Development and psychometric properties of a scale assessing the needs of caregivers of children with disabilities

Seok Hong Tan, M.P.H.

*Postgraduate Unit, Department of Social and Preventive Medicine, Faculty of Medicine, University Malaya, 50603 Kuala Lumpur, Malaysia*

## Abstract

**Background:** Planning and evaluation of health care services for children with disabilities requires information on their caregivers' needs.

**Objective:** This paper aims to present the development and psychometric properties of the Caregiver Needs Scale (CNS), a scale assessing the needs of caregivers of children with disabilities aged 0–12 years in Malaysia.

**Methods:** Development of the scale went through a multistage process of literature review, modification of an existing instrument, input from experts and feedback from service users. Literature review identified content domains and response options. An exploratory factor analysis (EFA) was undertaken to identify subscales of caregiver needs. The internal consistency reliability, convergent validity and discriminant validity of the new scale were examined.

**Results:** 273 caregivers of children with disabilities completed the fielded questionnaire. EFA revealed 4 subscales of caregiver needs: need for 'Help getting information and services for the child,' 'Help coping with the child,' 'Help getting child care' and 'Help with finances.' Three items with factor loading $<0.4$ were dropped. Cronbach's alpha coefficients of the subscales ranged from 0.813 to 0.903. Total CNS score correlated with number of child's needs and unmet needs. The score was also higher in families with financial and employment problems.

**Conclusion:** A new instrument was developed to assess the needs of caregivers of children with disabilities for use in the Malaysian population. The CNS showed satisfactory psychometric properties but further examination is warranted to confirm its validity. 

*Keywords:* Children with disabilities; Caregivers; Needs assessment; Instrument development; Psychometric properties

The World Disability Report 2011 recommends improving disability data collection as one of the efforts to overcome barriers that restrict participation for people with disabilities.[1] Knowledge of the demand, supply and existing efficiency of disability services is important to inform decisions on allocation of scarce resources in service systems. According to the Behavioural Model of Health Services Use, people's use of health services is a function of their predisposing characteristics, enabling resources and their need for care.[2] Hence, studying health care needs gives important information on the demand for health services which would impact on their utilization.

In Malaysia, the Persons with Disabilities (PWD) Act 2008 defines persons with disabilities as those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society.[3] This definition mirrors the one adopted by the Convention on the Rights of Persons with Disabilities.[4] The Ministry of Health, Ministry of Education and Department of Social Welfare under the Ministry of Women, Family and Community Development are the main stakeholders of service provision for children with disabilities in the country.

Disability in a child not only affects the child but also impacts on the child's family.[5–9] Prior to 1990, services for children with disabilities mainly targeted the medical and therapeutic needs of the child with the aim of improving child functioning, and it was only in later years that the focus of services expanded to include the needs of families living with a child with disability.[10] By understanding the circumstances of families caring for a child with disability, service providers can identify areas for improvement in the delivery of disability services.

Funding: This research is self-funded by the author.

Statement of conflict of interest: The author hereby declares there is no conflict of interest with other parties.

Corresponding author. Tel.: +60 12 5591396.

E-mail address: tanseokhong@yahoo.com

1936-6574/$ - see front matter 
http://dx.doi.org/10.1016/j.dhjo.2014.11.003

Asia-Pacific Journal of Public Health
1–11

DOI: 10.1177/1010539515592461
aph.sagepub.com
SAGE

# Unmet Health Care Service Needs of Children With Disabilities in Penang, Malaysia

**Seok Hong Tan, MBBS, MPH**[1]

## Abstract

Information on unmet health care needs reveal problems that are related to unavailability and inaccessibility of services. The study objectives were to determine the prevalence, and the reasons for unmet service needs among children with disabilities in the state of Penang, Malaysia. Caregivers of children with disabilities aged 0 to 12 years registered with the Penang Social Welfare Department in 2012 answered a self-administered mailed questionnaire. A total of 305 questionnaires were available for analysis (response rate 37.9%). Services that were very much needed and yet highly unmet were dental services (49.6% needed, 59.9% unmet), dietary advice (30.9% needed, 63.3% unmet), speech therapy (56.9% needed, 56.8% unmet), psychology services (25.5% needed, 63.3% unmet), and communication aids (33.0% needed, 79.2% unmet). Access problems were mainly due to logistic issues and caregivers not knowing where to obtain services. Findings from this study can be used to inform strategies for service delivery and advocacy for children with disabilities in Penang, Malaysia.

## Keywords

access problems, children with disabilities, health care services, needs assessment, unmet needs

## Introduction

The Asia Pacific region is home to two-thirds of the estimated 650 million persons with disabilities in the world[1] and the Global Burden of Disease study estimates that 1 in 20 children aged 14 years or younger live with a moderate or severe disability.[2]

The Convention on the Rights of the Child 1995 upholds the rights of a child with disability to receive health care and rehabilitation services in order for the child to achieve the fullest social integration and individual development. In 2012, members of the United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP), including Malaysia, adopted the Incheon Strategy to "Make the Right Real" for persons with disabilities in the region.

In Malaysia, persons with disabilities (PWDs) are registered with the Department of Social Welfare (DSW) under 7 categories: visual, hearing, physical, learning (inclusive of persons with intellectual disability and those with learning difficulties such as autism and dyslexia), speech,

[1]University Malaya, Kuala Lumpur, Malaysia

**Corresponding Author:**
Seok Hong Tan, Department of Social and Preventive Medicine, Faculty of Medicine, University Malaya, 50603 Kuala Lumpur, Malaysia.
Email: tanseokhong@yahoo.com

Health and Social Care in the Community (2016) doi: 10.1111/hsc.12325

# Assessing the needs of caregivers of children with disabilities in Penang, Malaysia

**Seok Hong Tan** MPH
Postgraduate Unit, Department of Social and Preventive Medicine, Faculty of Medicine, University Malaya, Kuala Lumpur, Malaysia

Accepted for publication 26 November 2015

**Correspondence**
Seok Hong Tan
Postgraduate Unit
Department of Social and Preventive Medicine
Faculty of Medicine
University Malaya
50603 Kuala Lumpur, Malaysia
E-mail: tanseokhong@yahoo.com

### What is known about this topic

- Disability in a child not only affects the child but also impacts on the child's family.
- Services for children with disabilities should address their family's needs.
- Expression of different family needs is influenced by child and family characteristics.

### What this paper adds

- Caregivers of children with disabilities in Malaysia need help getting information and services for their child the most, followed by help with finances.
- Families with younger and more severely disabled children need more help in all aspects of caregiving.
- Caregivers of children with learning disability need more information on services and ways of coping with their child.

## Abstract

Disability in a child not only affects the child but also presents socioeconomic and psychological impacts to the child's family. This study aims to describe the service needs of caregivers of children with disabilities in the state of Penang, Malaysia, and to determine the child and family characteristics predisposing to having more caregiver needs. A cross-sectional survey was conducted between February and June 2013 among caregivers of children aged 0–12 years with disabilities registered with the Penang Department of Social Welfare. Caregivers completed a self-administered mailed questionnaire containing a 20-item Caregiver Needs Scale (CNS). Each item in the CNS was rated on a 5-point Likert scale ranging from 'help not at all needed' to 'help extremely needed'. A total of 273 surveys were available for analysis (response rate 34.0%). The CNS contained four domains. The 'Help getting Information and Services for child' domain had the highest mean score (3.61, 95% CI: 3.46, 3.77) followed by 'Help with Finances' (3.29, 95% CI: 3.13, 3.45) and 'Help Coping with child' (3.11, 95% CI: 2.97, 3.25), while the 'Help getting Childcare' domain had the lowest mean score (2.30, 95% CI: 2.13, 2.47). Multivariate regression analysis identified caregivers of younger children and with more severe disability as having more caregiver needs in all domains. Besides that, caregivers of children with learning disability needed more help getting information and help with coping. Caregivers of children with learning and multiple disabilities needed more help getting childcare compared to children with other disability. Caregivers of Indian ethnicity, who had less than a tertiary education and who themselves had medical problems needed more help with finances. The findings on caregiver needs in this study can help inform planning of family support services for children with disabilities in Penang, Malaysia.

## Introduction

Services for children with disabilities should address the needs of their families because disability in a child not only affects the child but also impacts on caregiver health and family well-being (McConkey *et al.* 2006, Murphy *et al.* 2007, Schieve *et al.* 2011, Geere *et al.* 2013). Prior to 1990, services for children with disabilities mainly targeted the medical and therapeutic needs of the child with the aim of improving child functioning, and it was only in later years that the focus of services expanded to include the psychosocial needs of their families (King *et al.* 2002).

**APPENDIX D**

11th MOH-AMM Scientific Meeting 2015, Poster Presentation (Best Poster)

**Caring for a Child with Disability: How Supportive Are We?**

Tan Seok Hong[1], Wong Yut Lin[1]
[1]Department of Social and Preventive Medicine, University Malaya

Introduction: Parents of children with disabilities face many challenges in coping with the demands and needs of their child. Social support is therefore important to reduce coping demands and parental stress.

Objectives: To assess the helpfulness of informal and formal sources of support to families of children with disabilities.

Methodology: A cross-sectional survey was conducted in 2013 among caregivers of children with disabilities aged 0 – 12 years registered with the Penang Social Welfare Department. Caregivers answered a self-administered mailed questionnaire containing a modified 14-item Family Support Scale. Scores for each source of support ranged from 1 - 5, with higher scores indicating more helpfulness. Child and family characteristics associated with overall scores for informal and formal support were also determined.

Results and Discussion: A total of 305 questionnaires were available for analysis. Around half of the caregivers had someone to help them with the care of their disabled child. Most of the help was from grandparents, followed by siblings, other relatives and babysitter. Caregivers rated their spouse as most helpful (mean score 3.56), followed by the child's school/community-based rehabilitation centre/day care centre (2.52), other children in the family (2.30), maternal grandparents (2.24) and health care workers (2.19).

Families with fewer children and an older disabled child had lower overall scores for informal support. Indians and Chinese received less informal support than Malays who have more extensive and strong social networks. When informal supports are weak, formal sources of support be it government or non-governmental, become essential. Unfortunately, low and middle income families reported getting less support from formal sources compared to high income families. Indians and Chinese also received less formal support, even after adjusting for income level.

Conclusion: Formal sources of family support need to be more accessible to lower income families, and families of Indian and Chinese ethnicity.

11th MOH-AMM Scientific Meeting 2015, Poster Presentation

# Financial Impact on Families Caring for a Child with Disability: A Cross-sectional Study in Penang, Malaysia

Tan Seok Hong[1], Wong Yut Lin[1]
[1]Department of Social and Preventive Medicine, University Malaya

Introduction: Caring for a child with disability incurs higher cost than caring for a child without disability.

Objectives: To determine the magnitude of care expenditure and the financial impact on families caring for a child with disability in Malaysia.

Methodology: A cross-sectional survey was conducted in 2013 among 804 children with disabilities aged 0 – 12 years registered with the Penang Social Welfare Department. Caregivers answered a self-administered mailed questionnaire on family income and out-of-pocket care expenditure in the past one year. Caregivers were asked whether they felt the child's care expenditure had caused financial problem to the family, and whether they had have to leave their job to take care of the child.

Results and Discussion: A total of 305 questionnaires were available for analysis. The highest mean care expenditures were for child care (RM734), transportation RM528) and other non-medical care expenses (RM1085), while the lowest were for prescribed medicine (RM84) and dental treatment (RM25). Overall, 22.2% of families spent 10 – 19.99% of their income, and 32.0% spent ≥20% of their income on care expenditure for their disabled child. About one third (35.2%, 95% CI 29.3, 41.5) of caregivers reported having a sizable financial problem while 31.4% (95% CI 25.8, 37.6) had to leave their job to take care of their child.

Families of children with multiple disabilities (vs other disabilities, OR 2.25), higher severity of disability measured on the ABILITIES Index score (p value 0.015) lower education (None, primary or lower secondary education vs tertiary education, OR 2.43) and lower income level (bottom 40% vs top 20%, OR 2.54) were more likely to have financial problem. After adjusting for child disability and socioeconomic factors, caregivers of younger disabled children (0 – 3 years vs 7 – 12 years old, OR 4.19), of Indian ethnicity (vs Malays, OR 6.06) and who themselves had medical problems (vs none, OR 2.52) were more likely to report financial hardship.

Conclusion: Families of children with more severe disability, younger age, Indian ethnicity and lower socioeconomic status experienced more financial impact.

11th Asian Society of Paediatric Research Conference 2015, Poster Presentation

# Unmet Service Needs of Children with Learning and Multiple Disabilities in Penang, Malaysia: A Descriptive Analysis

Tan Seok Hong[1], Wong Yut Lin[1]
[1]Dept of Social and Preventive Medicine, University Malaya, Kuala Lumpur, Malaysia

Background: Children with disabilities require a multitude of disability related health care services. Studying their unmet service needs informs on the availability and accessibility to these services.

Objectives: The study aims to determine the magnitude and reasons for unmet needs among children with disabilities in the state of Penang, Malaysia. Children with learning disability and multiple disabilities represent the two largest groups of children with disabilities in Penang, thus a descriptive analysis of these two groups was undertaken.

Methods: A cross-sectional survey was conducted among children with disabilities aged 0 – 12 years registered with the Penang Social Welfare Department in 2012. Caregivers answered a self-administered mailed questionnaire assessing the child's unmet need for 17 specific medical services and assistive devices. Unmet need was defined as not fully receiving needed services.

Results: A total of 305 surveys were available for analysis. Out of this, there were 126 children with learning disability and 84 children with multiple disabilities. Children with learning disability had an average of 2.72 (95% CI 2.25, 3.19) services unmet out of 4.15 (95% CI 3.70, 4.60) needed, while children with multiple disabilities had an average of 3.44 (95% CI 2.78, 4.10) services unmet out of 7.31 (95% CI 6.69, 7.93) needed. The services most unmet for children with learning disability were communication aids, dietary advice, psychology services and dental services. For children with multiple disabilities, many did not have their need for vision aids, communication aids, hearing aids and dietary advice met. The most cited reason for unmet need in children with learning disability was that the place of service was too far, followed by caregivers not having time because of other commitments and no one to send the child for therapy. Among children with multiple disabilities, the most cited reasons were caregivers could not afford the cost of assistive devices and did not know where to obtain them.

More than three quarters of children with multiple disabilities, but only slightly more than half of children with learning disability received rehabilitation services in the past one year. Most children received therapy from government hospital, and a higher percentage of children with multiple disabilities received therapy from community based rehabilitation centres.

Conclusions: More attention should be directed at providing dietary advice and communication aids to both children with learning and multiple disabilities. Service providers should address the different reasons for unmet needs in the two groups of children.

**APPENDIX E**

**Conceptual models considered for framework of study**

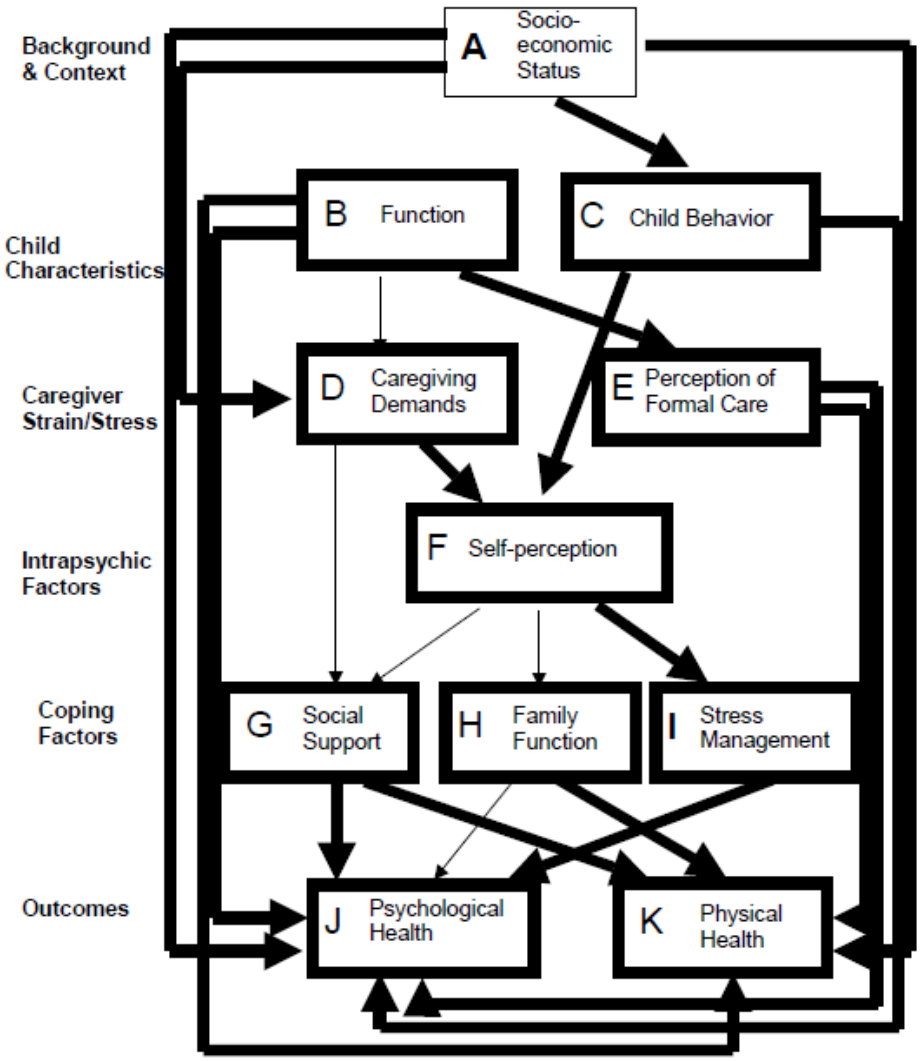


Figure E1: Conceptual model of caregiving process and caregiver burden among the paediatric population (Raina et. al., 2004)

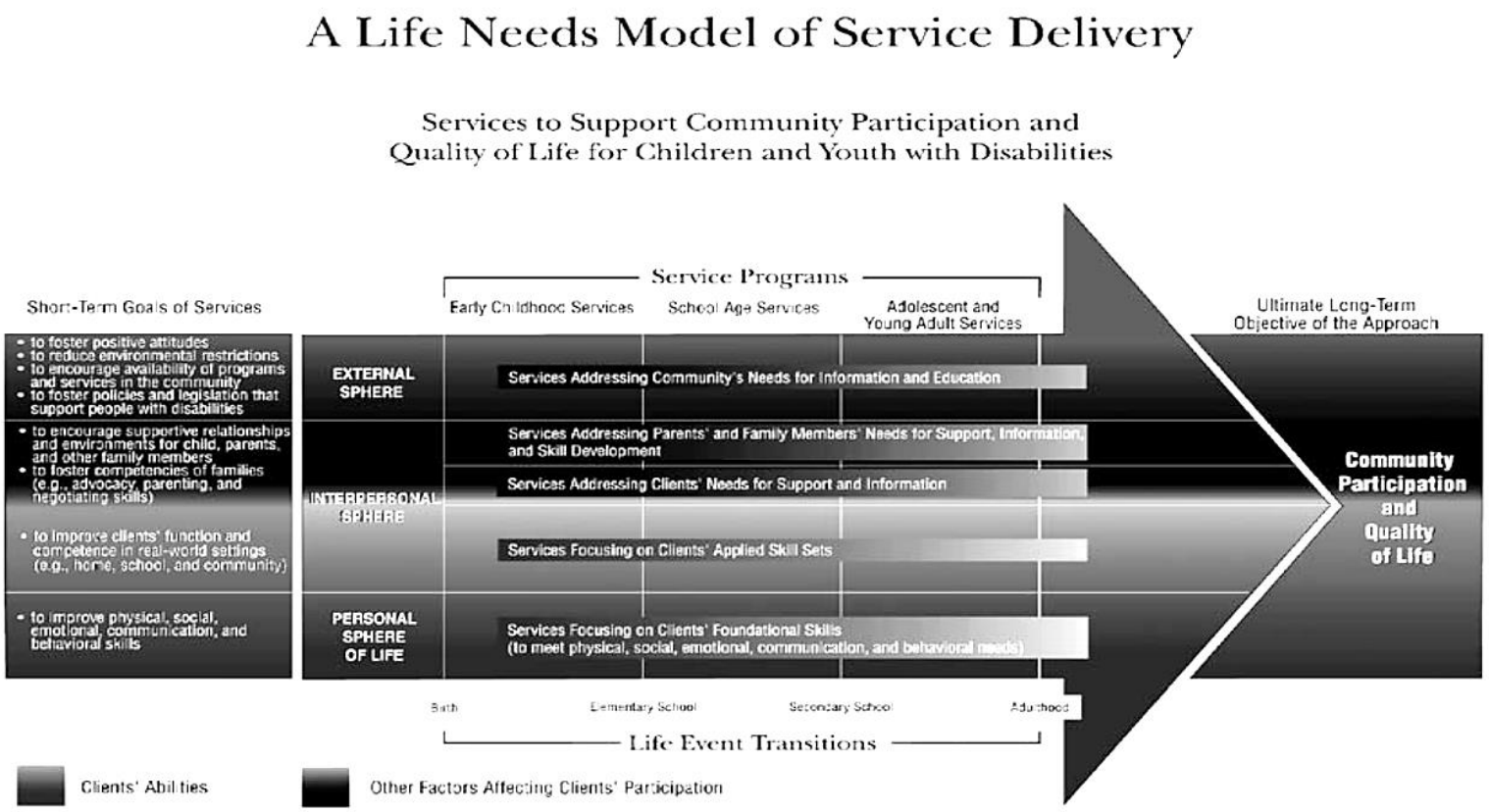


Figure E2: The Life Needs Model of Paediatric Service Delivery (King et al., 2002)

**APPENDIX F**

**Overview of data on children with disabilities in Malaysia**

The Department of Social Welfare (DSW), Ministry of Health (MOH) and Ministry of Education (MOE) maintain separate databases on children with disabilities.

The primary database is maintained by the DSW, compiled from data obtained from the registration system for persons with disabilities. The information in the registration system is limited to the number of registered persons with disabilities, and certain demographics of those registered. The DSW also has data on the amount of financial assistance given to persons with disabilities, the number of community based rehabilitation centres and the number of staff in the CBRs.

Data on children with disabilities are inaccurate and unreliable because the mechanism for these children to be counted relies heavily on the caregivers to register the child with the Department of Social Welfare. There may be a large number of children with disabilities who remain undetected or unregistered. Registration is voluntary and low registration numbers have been attributed to a fear that it may cause a child to be stigmatised, or might pre-determine the child's enrolment into special needs education in the national school system; instead of assessing a priori whether the child can cope under mainstream schooling.

Data on the total number of registered PWDs is obtained from new registrations added to existing numbers already in the system, so data on those who are not in the system is never captured. Data on children with disabilities is rendered even more inaccurate because since figures according to age group are also cumulative, there is no mechanism to take into account the movement from one age group to another as the child grows up.

The MOH collects statistics on the number of newly diagnosed children with special needs through registration data compiled from hospitals and health clinics. The use of a registration book started at health clinics in 1998 and expanded to paediatric clinics in hospitals in 2003. From 2010 onwards, the registration book is available in all MOH primary care clinics, clinics of all disciplines in MOH hospitals, other government hospitals such as the army hospital, university hospitals and even private hospitals. In this database, "special needs" are classified as hearing impairment, visual impairment, physical disability, cerebral palsy (hemiplegia, diplegia or quadriplegia), late

development, Down syndrome, autism, attention deficit hyperactive disorder (ADHD), mental disability, specific learning difficulties, slow learner and others.

A monthly return has to be submitted online by the district health office to the Family Health Development Division at federal level. Information collected from the return include the number of new cases according to age and type of disability, and the number of new cases undergoing rehabilitation programme according to place of rehabilitation. Information on staff workload is also available via data on the number of new, follow-up and drop-out cases, the total visits of children with special needs for rehabilitation in clinic, and total cases with home visits or attending community based rehabilitation centres.

The MOE collects statistics on the number of enrolments in the special needs education system for children with disabilities in government-run schools. Between 2010 to 2013, the total number of enrolments in the government's special needs education system was constant at around 1% of the total number of school enrolments. These statistics do not take into account the number of children with disabilities registered in private education institutions. Children with disabilities who do not qualify for the special needs education system but who are in the mainstream education system, and children who are out of school, are also not captured in the data.

Malaysia has yet to conduct a census to screen the population for disability, to arrive at a more accurate estimation of disability prevalence in the country. The National Health and Morbidity Survey (NHMS) is a nationwide health survey, but so far, disability has not been a prominent feature in this survey. The first NHMS was carried out in 1986, and every 10 years after that. Since 2006, it was carried out every 5 years and since 2015, it will be carried out every year with emphasis on different topics.

Reliable statistics on the actual number of children with disabilities in the country is not available as Malaysia lacks a comprehensive and structured system of data collection and compilation for children wtih disabilities. Even though Malaysia reports a disability prevalence rate of 1.0 – 1.5%, this is only based on the number of registered persons with disabilities. This prevalence rate is likely a gross underestimation of the true number of persons with disabilities compared to the often cited WHO estimation of 10%. According to NHMS III (2006), only 44% of the expected number of physically disabled persons was registered. Out of this, one third of physically disabled children did not register.

**APPENDIX G**

## Content domains and response scales for instruments used to assess child and family needs

| INSTRUMENT OR SURVEY TITLE | POPULATION STUDIED | CONTENT DOMAINS | RESPONSE SCALES |
|---|---|---|---|
| Family Needs Survey (FNS) and modified versions of it<br><br>(Bailey Jr, Blasco & Simeonsson, 1992) | Children with disabilities and children with chronic health conditions | 6 domains:<br>Needs for Information<br>Needs for Support<br>Needs for help in Explaining the child's condition to others<br>Needs for Community services<br>Financial needs<br>Needs for help in Family functioning<br><br>The revised FNS re-categorized the original items into 7 domains:<br>Information Needs<br>Family and Social Support Needs<br>Financial Needs<br>Explaining to Others<br>Child Care<br>Professional Supports<br>Community Services | 1 = Definitely do not need help with this<br>2 = Not sure<br>3 = Definitely need help with this<br><br>A sum score for each category and total sum score (with response 3) were calculated |
| Unmet Needs of Children with Chronic Health Conditions<br><br>(Perrin, Lewkowicz & Young, 2000) | Children with chronic health conditions | Information needs:<br>Information about child's condition and treatment<br>Advice about child's behaviour and development<br>Advice about what to expect as child gets older<br>Care coordination<br><br>Contact needs:<br>Discussion groups for child and siblings<br>Discussion groups for parents<br>Contacts with other families<br><br>Counselling needs:<br>Counselling for parents or other family members<br>Counselling for child<br><br>Specific help needs:<br>Arrangements for child's school programmes<br>Care for child so parents can get away<br>Child care while parents work<br>Advice on health insurance or other financial assistance<br>Legal assistance<br>Modifications to home/professional homemaker services/help with day-to-day jobs like babysitting, shopping<br>Transportation to medical or other services<br>Social or recreational activities for child,<br>Home nursing care/specialized treatments | The respondents noted which of the items the family "would benefit from"<br><br>Unmet need was defined as child going without a needed service altogether |

| INSTRUMENT OR SURVEY TITLE | POPULATION STUDIED | CONTENT DOMAINS | RESPONSE SCALES |
|---|---|---|---|
| | | Special equipment<br><br>Other items:<br>Genetic counselling<br>Education for child about condition and treatment<br>Information for adolescents<br>Job training and work opportunities for child | |
| Family Partners Survey<br><br>(Warfield & Gulley, 2006) | Children with special health care needs in the US | Need for 6 specialty services:<br>Specialist medical doctors<br>Mental health clinicians<br>Physical therapists<br>Occupational therapists<br>Speech therapists<br>Home health providers | In each section, respondents indicated whether their child needed the given service over the past year (Yes/No) and if Yes, whether it was received (Yes/No). |
| Needs questionnaire modified from the FNS and Nijmegen Questionnaire on Child Rearing Situations<br><br>(Hendriks, Moor, Oud & Franken, 2000) | Children with motor or multiple disabilities attending therapeutic toddler classes in Dutch rehabilitation centres | 5 domains:<br>Need for understanding the child's disability and for integrating therapy at home<br>Need for information on community services<br>Need for help in parenting<br>Need for respite care<br>Need for support and for help in explaining the child's condition to others<br><br>Financial Needs in the original FNS was asked as a single question under Needs for help in family functioning | Parents were asked to indicate the extent to which they agreed with each statement of help needed ranging from "totally disagree" (score 0) to "totally agree" (score 4)<br><br>For each subscale, need scores were computed by summing the responses to the items in the subscale and dividing by the number of items<br><br>Answers to amount of help received were rated on a 3 point scale of "enough", "some, but not enough" and "no, although needed". |
| US National Survey of Children with Special Health Care Needs (NSCSHCN)<br><br>(Blumberg et al., 2008) | Children younger than 18 years with special health care needs<br><br>The children were identified through a screener, as part of the State and Local Area Integrated | Health care needs (any of 14 primary and specialty care services, ancillary services, supplies and equipment):<br>Well child check-up<br>Preventive dental care<br>Other dental care or orthodontia<br>Specialty doctor<br>Prescription medication<br>Physical, occupational or speech therapy<br>Mental health care or counselling<br>Substance abuse treatment and counselling (for those aged >8 years old)<br>Home health care<br>Eye glasses or vision care | Respondents were asked whether the child needed a service in the past 12 months/ since his or her birth (Yes/No).<br>If Yes, whether the child received all the needed service (Yes/No) and received any of it in the past 12 months/ since his or her birth (Yes/No). |

| INSTRUMENT OR SURVEY TITLE | POPULATION STUDIED | CONTENT DOMAINS | RESPONSE SCALES |
|---|---|---|---|
| | Telephone Survey (SLAITS) programme | Hearing aids or hearing care<br>Mobility aids or devices<br>Communication aids or devices<br>Durable medical equipment<br><br>Family support services:<br>Respite care<br>Genetic counselling<br>Mental health care or counselling | Respondents were asked whether any family members needed the service in the past 12 months (Yes/No).<br>If Yes, whether the family member received all the needed service (Yes/No) and received any of it in the past 12 months/ since the child's birth (Yes/No).<br><br>Unmet need was defined as not receiving *all* the needed service |
| Participation and Activity Limitation Survey (PALS), Canada | Children with disabilities aged 15 years or younger in Canadian provinces identified through a screener | Caregivers' needs for respite care:<br>Help or additional help with everyday housework, to attend to other family responsibilities, to take time off for personal activities<br><br>Child care programme or service, health service for child | Need for help or additional help for respite care (Yes/No)<br><br>Being refused a child care programme or service (Yes/No)<br><br>Not receiving health services for their child when needed (Yes/No) |
| Child Content Questionnaire from the New Zealand Household Disability Survey | Children estimated to have a physical disability from the survey | Health professionals, therapists or healers<br>Medication<br>Special diet<br>Disposable items<br>Special equipment,<br>Help with child's personal care<br>Help with household tasks<br>Respite care<br>Help with repairs or maintenance to the home or property<br>Modifications to a private motor vehicle<br>Transport costs<br>Special features to enter or leave home<br>Special features inside home | Respondents were asked in the last 12 months, has the child needed any of the service but were not able to get it (Yes/No).<br><br>They were also asked the reasons for not getting it. (too costly/could not afford, applied for financial help but not eligible, did not know could apply for financial help or where to apply, other reason, specify) |
| Need for Help Questionnaire<br><br>(Douma, Dekker & Koot, 2006) | Adolescent and youth 0 – 24 years with moderate to borderline intellectual disabilities | Need for support:<br>7 specific types of support (a friendly ear for the parents/ someone to talk to, information, activities for the child, respite care, practical or material help, child mental health care and parental counselling aimed at better handling their child's problems) | To what extent in the past year they needed any of 7 specific types of support because of their child's emotional or behavioural problems ("no need", "some need", "reasonably strong need" and "very strong need") |

| INSTRUMENT OR SURVEY TITLE | POPULATION STUDIED | CONTENT DOMAINS | RESPONSE SCALES |
|---|---|---|---|
| | | | Level of need was dichotomized to low need (some need) and high need (reasonably strong need and very strong need) |
| Unmet Health Care Needs and Impact on Families survey<br><br>(Thyen, Sperner, Morfeld, Meyer & Ravens-Sieberer, 2003) | Children with disabilities aged 0 – 18 years from the ambulatory case register at a large children's hospital in northern Germany | Preventive medical care:<br>Regular doctor<br>Monitoring of growth and development<br>Immunizations<br>Well-child visits<br><br>Coordination and communication:<br>Arrangements if child needs to see a specialist<br>Communicate with kindergarten/school/child's therapists<br><br>Education about illness:<br>Explanation of child's condition/disability<br>Genetic counselling<br>Counselling about special appliances<br><br>Psychosocial counselling:<br>General advice on educational or behavioural problems<br>Talk to someone who understands the special problems of raising a child with disability<br>Information on parent groups or self-help organizations<br>Information on social services<br>Information about family support programmes | 14 items<br><br>4 categorical response format for unmet needs:<br>1 Received a service<br>2 Received it partly<br>3 Did not receive it and did not need it<br>4 Did not receive it but needed it<br><br>Response 4 was considered unmet need |
| Child Health Care Questionnaire on Satisfaction, Utilization and Needs (CHC-SUN) by the European DISABKIDS Group<br><br>(Schmidt, Thyen, Chaplin & Mueller-Godeffroy, 2007) | Children with chronic health conditions receiving treatment in paediatric specialty clinics in 7 European countries | Physiotherapy,<br>Occupational therapy, Speech therapy,<br>Social worker services, Psychological counselling,<br>Nurse services at home, Rehabilitation services<br>School Services,<br>Health education,<br>Short-term respite care,<br>Self-help groups,<br>Telephone counselling,<br>Supply with medical equipment,<br>Supply with physical aids,<br>Coordination of services | Utilization within the last year (Yes/No)<br><br>Difficulty accessing the service (5 point Likert scale ranging from "extremely difficult" to "not difficult")<br><br>4 categorical response format for unmet needs:<br>1 Received a service<br>2 Received it partly<br>3 Did not receive it and did not need it<br>4 Did not receive it but needed it<br><br>Response 4 was considered unmet need |

| INSTRUMENT OR SURVEY TITLE | POPULATION STUDIED | CONTENT DOMAINS | RESPONSE SCALES |
|---|---|---|---|
| Service Needs Questionnaire (SNQ)<br><br>(Leung, Lau, Chan, Lau & Chui, 2010) | Children with learning and/or behavioural problems aged 6 to 12, who visited the Child Assessment Service (CAS) in Hong Kong | Emotional support<br>Explaining child's condition to others<br>Professional support services<br>Stress management<br>Help dealing with child's emotion and behaviour<br>Information about child's special education needs<br>Help in seeking services<br>Training services by professionals<br>Learning support services for child<br>Resources to support child learning<br>Information on how to help child's learning | 5 point Likert scale ranging from "do not endorse at all" to "endorse a lot"<br><br>A sum score for all the items is calculated |
| Supports and Services inventory of the Partnership and Family Quality of Life questionnaire<br><br>(Kertoy et al., 2012) | Children with special needs 0 – 16 years randomly selected from 3 children's treatment centres in Ontario, Canada | Assessment of services specific to the child:<br>Special equipment to help child live, learn and grow<br>Health services (medical evaluation, nutrition, nursing)<br>Hearing and/or vision services<br>Physical and/or occupational therapy<br>Speech and/or language services<br>Special education services<br>Counselling and psychological services<br>Behaviour support<br>Transportation and/or mobility services<br>Self-care skills training<br>Service co-ordination<br>Transition services<br>Employment or vocational services<br><br>Services specific to the family:<br>Respite care<br>Child care<br>Money to help pay bills<br>Homemaker and/or housekeeping services<br>Transportation<br>Support groups<br>Counselling<br>Sibling support<br>Parent or family training<br>Information about specific disabilities<br>Information about where to get services for the child<br>Information about where to get services for the family<br>Information about legal rights | Parents were asked if the service listed was needed and if the response is yes, they were then asked how much of the service was received (none, some but not enough, enough). |

References:


Bailey Jr, D. B., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation, 97*(1): 1-10.

Blumberg, S. J., Welch, E. M., Chowdhury, S. R., Upchurch, H. L., Parker, E. K., & Skalland, B. J. (2008). Design and operation of the National Survey of Children with Special Health Care Needs, 2005-2006. *Vital And Health Statistics. Ser. 1, Programs And Collection Procedures*(45): 1-188.

Douma, J. C. H., Dekker, M. C., & Koot, H. M. (2006). Supporting parents of youths with intellectual disabilities and psychopathology. *Journal of Intellectual Disability Research, 50*(Part 8): 570-581.

Hendriks, A. H., Moor, J. M. D., Oud, J. H., & Franken, W. M. (2000). Service needs of parents with motor or multiply disabled children in Dutch therapeutic toddler classes. *Clinical Rehabilitation, 14*(5): 506-517.

Kertoy, M. K., Russell, D. J., Rosenbaum, P., Jaffer, S., Law, M., McCauley, D., & Gorter, J. W. (2012). Development of an outcome measurement system for service planning for children and youth with special needs. *Child: Care, Health and Development, 39*(5): 750-759.

Leung, C., Lau, J., Chan, G., Lau, B., & Chui, M. (2010). Development and validation of a questionnaire to measure the service needs of families with children with developmental disabilities. *Research in Developmental Disabilities, 31*: 664 - 671.

Perrin, E. C., Lewkowicz, C., & Young, M. H. (2000). Shared vision: Concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. *Pediatrics, 105*(Supplement 2): 277-285.

SASD. Participation and Activity Limitation Survey 2006: Technical and Methodological Report: Social and Aboriginal Statistics Division, Statistics Canada.

Schmidt, S., Thyen, U., Chaplin, J., & Mueller-Godeffroy, E. (2007). Cross-cultural development of a child health care questionnaire on satisfaction, utilization, and needs. *Ambulatory Pediatrics, 7*(5): 374-382.

SNZ. (2006). Disability Survey New Zealand: Child Content Questionnaire: Statistics New Zealand.

Thyen, U., Sperner, J., Morfeld, M., Meyer, C., & Ravens-Sieberer, U. (2003). Unmet health care needs and impact on families with children with disabilities in Germany. *Ambulatory Pediatrics, 3*(2): 74-81.

Warfield, M. E., & Gulley, S. (2006). Unmet need and problems accessing specialty medical and related services among children with special health care needs. *Maternal and Child Health Journal, 10*(2): 201-216.

**APPENDIX H**

**Development and psychometric properties of Caregiver Needs Scale**

Introduction:

The Caregiver Needs Scale was developed to assess the needs of caregivers of children with disabilities in this study.

Locally, Suriati et al (2011) have used the original version of the FNS to investigate the unmet needs among caregivers of children with disabilities recruited from community based rehabilitation centres in Selangor, a state in central Malaysia. The FNS translated to the Malay language was found to have good internal consistency reliability with Cronbach's alpha coefficient of 0.91 overall, and ranging from 0.74 to 0.88 for the respective subscales.

Cronbach's alpha coefficient is sensitive to the number of items in the scale, and inter-item correlation may be increased by simply adding the number of items within each subscale (Embretson, 1999). Although the FNS has shown good internal consistency reliability in the Malaysian population, other psychometric properties of the FNS such as construct validity and factor analysis have not been examined.

Methodology:

a) Modification of Family Needs Survey for Caregiver Needs Scale

Because the Family Needs Survey (FNS) and modified versions of it have been most widely used to measure family needs, the CNS was modelled based on the FNS.

The original FNS has 35 items categorized into 6 domains: 'need for information', 'need for social support', 'need for community services', 'need for financial support', 'need for help with family functioning' and 'need for help explaining to others'. A revision of the FNS resulted in the items being re-categorized into 7 domains (Bailey Jr, Blasco & Simeonsson, 1992). 'Need for family and social support', 'need for professional support' and 'need for help with child care' replaced 'need for social support' and 'need for help with family functioning' domains.

The Caregiver Needs Scale retained the domains of 'need for information', 'need for social support', 'need for community services' and 'need for financial support' from the original FNS. The 'need for help with family functioning' and 'need for help explaining

to others' domains were not included in the new scale because these subscales were considered to be of less direct relevance to service providers in the context of Malaysian culture. In Asian societies, families tend to keep family problems within the family unit and there may be minimal expectation for formal support services to help out with these aspects.

The proportion of both mothers and fathers who needed 'help explaining to others' was comparatively lower than other constructs in the Japanese version of the FNS (Ueda et al., 2013). Besides that, 'need for help with family functioning' was found to be the least important service need in a Dutch study among parents of children with motor or multiple disabilities (Hendriks, Moor, Oud & Franken, 2000).

In the end, a total of 20 items were generated for the Caregiver Needs Scale, grouped into four domains (table H1).

Table H1: Items generated for the Caregiver Needs Scale grouped by their domains

| Help finding Community Services | Information Needs | Social Support Needs | Financial Support Needs |
|---|---|---|---|
| Finding transport to medical appointments | Information on child's disability | Having someone to talk to about problems | Help with paying for daily expenses |
| Finding trained person for day care | Information on current services available for child | Learning how to manage stress | Help with paying for child's education/ therapy |
| Finding respite care | Information on future services for child | Opportunities to talk to other parents of disabled children | Help with paying for special equipment/ toys that child needs |
| Finding suitable education/therapy for child | Information on how to integrate therapy into daily activities | Having more time for oneself | Help with paying for child care |
| Finding social or recreational activities for child | Information on how to handle child's behaviour | | |
| Getting care coordination | Information on how to play or communicate with child | | |

In the FNS, respondents were asked to select one of three responses for each item: 1 = definitely do not need help with this, 2 = not sure, 3 = definitely need help with this, and the total number of reported needs was obtained by summing the number of items rated as 3.

For the CNS, the response to each item was scored on a Likert scale: 1 = Help not at all needed, 2 = Help rarely needed, 3 = Help sometimes needed, 4 = Help very much needed, 5 = Help extremely needed. A total score could be calculated for the entire scale, and mean scores could be calculated for each subscale. Response for each item were also grouped into 3 categories: Help definitely needed (response 4 and 5), Help sometimes needed (response 3) and Help not needed (response 1 and 2).

b) Statistical analysis for psychometric testing of the Caregiver Needs Scale

The adequacy of data for factor analysis was tested using Kaiser-Meyer-Olkin test and Bartlett's test of sphericity. Exploratory factor analysis was conducted to distinguish subscales of needs. Principal axis factoring was used as the extraction method, since the indicators were reflective indicators. Rotation was performed by promax method, taking into consideration an anticipated correlation between factors. The number of factors to be extracted was determined by the Eigen value of $\geq 1$.

The Caregiver Needs Scale was then examined for internal consistency, convergent validity and discriminant validity.

It was hypothesized that the more health care needs the child has and the more these needs were unmet, the higher the caregiver needs score would be. Child health care needs were measured by the number of services the child needed, whereas unmet needs were measured by the number of needed services which were not fully received.

Our questionnaire included questions on whether the family experienced financial and employment problems as a result of taking care of a child with disability. Families who had financial or employment problems were hypothesized to have more needs.

The One-sample Kolmogorov Smirnov test revealed a normal distribution of the obtained Caregiver Needs score. Therefore, Pearson's correlation was assessed between CNS score and number of needs/unmet needs. T-tests were performed to assess whether CNS score could discriminate between families having financial problem and employment problem from those who did not.

Results of psychometric testing:

Out of the 804 questionnaires mailed out, 273 caregivers answered the CNS completely, giving a response rate of 34%. For psychometric testing, the sample was not weighted.

a) Exploratory Factor Analysis (EFA)

All scale items were included in factor analysis. In our study, >15% of respondents expressed a definite need for help in all the items (response 4 and 5). If response 3 (help sometimes needed) was included, all items had >30% of respondents expressing their need for help.

In other studies, Hendriks et al excluded items with an extremely skewed distribution from factor analysis (those items on which <15% of the participants expressed a need for help), whereas Ueda et al excluded items where <20% of mothers and fathers expressed they needed help with.

The adequacy of the sample for extraction of the factors was confirmed by a high Kaiser-Meyer-Olkin value (0.930) and Bartlett's test result ($p<0.001$). Exploratory factor analysis of the Caregiver Needs Scale revealed that 11 items had factor loading >0.7, 7 items had factor loading between 0.4 and 0.7 and 2 items had factor loading <0.4. Most studies identified items as belonging to a factor if the factor loading is >0.4.

The item 'help finding transport to medical appointments' cross-loaded into 2 constructs, with both factor loading values <0.4. Another item 'help finding social or recreational activities for child' also had factor loading <0.4. The EFA after removal of these 2 items revealed an additional item 'finding suitable education for child' did not fit well into the scale, thus this item was also removed.

The final EFA showed that all remaining items in the CNS had factor loadings of >0.4 (table H2). Four constructs were extracted, explaining 65% of the total variance. The first construct explained the majority of the total variance (47.9%). The four constructs extracted were characterized as need for (i) Help getting information and services for child, (ii) Help coping with the child, (iii) Help getting child care and (iv) Help with finances.

Table H2: Caregiver Needs Scale and its factor loadings

| | Factor | | | |
|---|---|---|---|---|
| | 1 | 2 | 3 | 4 |
| Information on current services available for child | 0.960 | | | |
| Information on future services for child | 0.929 | | | |
| Information on how to integrate therapy into daily activities | 0.774 | | | |
| Information on child's disability | 0.688 | | | |
| Getting care coordination | 0.485 | | | |
| Learning how to manage stress | | 0.992 | | |
| Finding someone to talk to about problems | | 0.931 | | |
| Opportunities to talk to other parents | | 0.740 | | |
| Information on how to play or communicate with child | | 0.530 | | |
| Information on how to handle child's behaviour | | 0.529 | | |
| Having more time for oneself | | 0.458 | | |
| Finding trained person for day care | | | 0.898 | |
| Finding respite care | | | 0.858 | |
| Help paying for child care | | | 0.740 | |
| Help with paying for daily expenses | | | | 0.835 |
| Help with paying for child's education/ therapy | | | | 0.822 |
| Help with paying for special equipment/toys | | | | 0.450 |
| Eigen value | 8.489 | 1.548 | 1.222 | 1.119 |
| Explained variance (%) | 47.890 | 7.241 | 5.261 | 4.577 |
| Cumulative variance (%) | 47.890 | 55.132 | 60.394 | 64.971 |
| Cronbach's alpha | 0.891 | 0.903 | 0.844 | 0.813 |

The construct 'Help getting information and services for child' consists of 4 out of 6 items in the original construct of 'need for information' plus one other item 'help getting care coordination'. The 'Help coping with the child' construct contained all 4 items in the original 'need for social support' construct and 2 items from the original 'need for information' construct related to parenting a child with disability. Items related to finding and paying for child care services went into the new construct 'Help getting child care'. The remaining 3 items in the original 'need for financial support' construct were retained and the construct was re-labelled as 'Help with finances'.

Examination of intercorrelations between constructs or subscales showed moderate correlations (correlation coefficients 0.566 to 0.653). This is acceptable because for subscales to be reasonably unrelated, intercorrelations should only be weak or moderate.

b) Internal consistency reliability, convergent validity and discriminant validity

The Caregiver Needs Scale was tested for internal consistency, convergent validity and discriminant validity using the 17 items that fit well into the scale. The 17 item CNS had a normal distribution with a mean score of 53.33 ± 16.09 and skewness of -0.258.
The Cronbach's alpha coefficient for the total scale was 0.936, and ranged from 0.813 to 0.903 for each subscale. In addition, the highest correlation for each item with other items in each subscale was <0.85, so there is no problem with multicollinearity.
The correlations between the CNS score and number of services needed by the child; and between CNS score with number of services not fully received were examined. CNS score was moderately correlated with number of services needed (r = 0.450, p value <0.001) and with number not fully received (r = 0.312, p value <0.001), indicating that the more needs and unmet needs the child has, the more needs the caregiver has.
CNS score could differentiate between those having financial problem (mean score 55.30 ± 15.02) from those who did not (mean score 39.42 ± 16.00, mean difference 15.88, 95% CI 10.18, 21.59, p value <0.001). It could also differentiate between those having employment problem (mean score 55.50 ± 15.09) from those who did not (mean score 45.85 ± 17.43, mean difference 9.65, 95% CI 5.19, 14.11, p value <0.001).

Discussion:

The development of the Caregiver Needs Scale (CNS) could be enhanced by further qualitative approaches in the initial phase of identifying content domains. Focus group discussions among service users and service providers could be helpful in getting more extensive input on caregiver needs, but this could not be organized due to resource constraints for this study. Besides that, content validity of a scale can be determined by asking experts to rate each item according to its essentialness (measured as content validity rate) and relevance (measured as content validity index) (Wynd, Schmidt & Schaefer, 2003).

After exploratory factor analysis (EFA), four subscales consisting of 17 items were identified. Another 3 items ('help finding suitable education for child', 'help finding social or recreational activities for child' and 'help finding transport to medical appointments') did not fit well into the scale.

However, sometimes items that exhibit poor fit can be retained because they are deemed to be important or may have policy implications. "Help finding transport to medical appointments" did not load into any construct, but this item is important in identifying a specific family need. The direct assessment of transportation issues and its impact on family quality of life was more beneficial than when it was indirectly assessed as a barrier to accessing health care and service support (Samuel, Rillotta & Brown, 2012). It is recommended that service providers who are interested to know about caregivers needs for the remaining 3 items can still retain them in the questionnaire, but these items should not be included in subsequent analyses involving the total scale or subscales.

If a scale has high internal consistency, most measurement experts agree that the Cronbach's alpha coefficient should be between 0.70 and 0.90. If item correlations are too high, it is likely that some items are redundant and should be removed from the test. The overall Cronbach's alpha coefficient for the CNS was 0.936, and for the subscale of 'Help coping with the child', it was 0.903, both of which are slightly high.

The correlations between individual items in each subscale were examined and all except one of the correlation coefficients were less than 0.80. The highest inter-item correlation in the whole scale was between 'learning stress management techniques' and 'having someone to talk to about problems' (correlation coefficient 0.834) in the subscale of 'Help coping with the child'. Talking to someone about the problems one faces can be a way of coping with stress. This could explain the relatively high correlation between these two items. To enable the individual items to be more distinct, examples of stress management techniques, such as relaxation therapy or exercise, can be added as an explanation to the item 'learning how to manage stress'.

A confirmatory factor analysis (CFA) could be tackled in future studies. CFA is a more rigorous examination of scales and is used to confirm if items in the scale are measuring what they are supposed to measure (MacCallum, 2003). CFA examines the correlations among measured items along a single latent trait for each scale and enables an understanding of how the latent trait may be improved by adding or removing items.

The limitation of the study to test the psychometric properties of the CNS is that children with learning disability were underrepresented in the sample. Nevertheless, out of 273 caregivers who completed the CNS, 111 were caregivers of children with learning disability, which is quite a sizable number.

It is acknowledged that the experiences of each family cannot fully be represented by scale scores, yet some quantitative measurement of family needs is invaluable to give service providers an idea of where to focus their priorities and allocate resources. The CNS is not meant to replace individual assessment of service needs, but it can serve as a springboard for service providers working directly with individual families to delve deeper into the family's particular needs for follow-up action and practical intervention.

The evaluation of subscales is important for the CNS because need for help may vary considerably according to the different domains. If the scores are totalled up or averaged, it may give a false impression on the level of need. A low score and a high score will give an average of a medium score, where in reality the caregiver may need a lot of help in one domain but may not need help at all in another domain.

Conclusion:

Future studies can be undertaken to confirm the validity and utility of the scale for caregiver needs assessment in Malaysia and in other Southeast Asian countries.


Bailey Jr, D. B., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation, 97*(1): 1-10.

Embretson, S. E. (1999). Generating items during testing: Psychometric issues and models. *Psychometrika, 64*: 407-433.

Hendriks, A. H., Moor, J. M. D., Oud, J. H., & Franken, W. M. (2000). Service needs of parents with motor or multiply disabled children in Dutch therapeutic toddler classes. *Clinical Rehabilitation, 14*(5): 506-517.

MacCallum, R. C. (2003). Working with imperfect models. *Multivariate Behavioral Research, 38*: 113-139.

Samuel, P. S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal Of Intellectual Disability Research, 56*(1): 1 - 16.

Suriati, S., Zainiyah, S. S., Lye, M., & Norlijah, O. (2011). Assessing the unmet needs among caregivers of children with disabilities at the community-based rehabilitation centres in Selangor. *Malaysian Journal of Public Health Medicine, 11*(2): 32 - 40.

Ueda, K., Bailey Jr, D. B., Yonemoto, N., Kajikawa, K., Nishigami, Y., Narisawa, S., . . . Kodama, K. (2013). Validity and reliability of the Japanese version of the Family Needs Survey. *Research in Developmental Disabilities, 34*(10): 3596-3606.

Wynd, C., Schmidt, B., & Schaefer, M. A. (2003). Two quantitative approaches for estimating content validity. *Western Journal of Nursing Research, 25*: 508-518.

**Psychometric properties of the modified Family Support Scale**

A total of 267 caregivers answered the modified FSS completely. The 14 item FSS had a normal distribution, with a mean score of 25.96 ± 11.81 and skewness of 0.349.

a) Exploratory Factor Analysis (EFA)

The adequacy of the sample for extraction of the factors was confirmed by a high Kaiser-Meyer-Olkin value (0.830) and Bartlett's test result ($p<0.001$). Exploratory factor analysis of the FSS revealed that 8 items had factor loading >0.7 and 6 items had factor loading between 0.4 and 0.7. Four constructs were extracted, explaining 64.7% of the total variance. All formal support sources loaded into the same construct while informal support sources loaded into three constructs.

Table H3: Family Support Scale and its factor loadings

| | Factor | | | |
|---|---|---|---|---|
| | 1 | 2 | 3 | 4 |
| Paternal grandparents | 0.548 | | | |
| Maternal grandparents | 0.718 | | | |
| Paternal relatives | 0.799 | | | |
| Maternal relatives | 0.836 | | | |
| Spouse | | | | 0.510 |
| Friends | | | 0.922 | |
| Other children | | | | 0.708 |
| Colleagues | | | 0.746 | |
| Other parents of disabled children | | | 0.591 | |
| Health care workers | | 0.586 | | |
| School/ PDK/ day care centre | | 0.550 | | |
| Social Welfare department | | 0.828 | | |
| Education department | | 0.744 | | |
| NGO/ voluntary organizations | | 0.440 | | |
| Eigen value | 5.070 | 1.644 | 1.231 | 1.110 |
| Explained variance (%) | 36.214 | 11.743 | 8.795 | 7.926 |
| Cumulative variance (%) | 36.214 | 47.957 | 56.752 | 64.678 |
| Cronbach's alpha | 0.794 | 0.762 | 0.777 | 0.507 |

b) Internal consistency reliability, convergent validity and discriminant validity

The Cronbach's alpha for the modified 14 item FSS was 0.841, for informal FSS was 0.779 and for formal FSS was 0.762. There was no problem with multicollinearity.

To test for convergent validity, Pearson's correlation was assessed between FSS score and Caregiver Needs subscale scores, as well as number of services not fully received (unmet needs). To test for discriminant validity, t-tests were performed to determine whether FSS score could discriminate between families having financial problem and employment problem from those who did not.

FSS score did not correlate with any of the Caregiver Needs subscale scores (r = -0.078 to 0.070) or number of unmet needs (r = -0.001). FSS score could not differentiate between those having financial problem from those who did not. But it could differentiate between those having employment problem (mean score 24.73 ± 11.46) from those who did not (mean score 30.22 ± 12.11, mean difference 5.49, 95% CI 2.11, 8.86, p value 0.002).

The original FSS has been tested for (1) internal consistency reliability: coefficient alpha (on the 18-item scale) = 0.77 (Dunst, Jenkins & Trivette, 1984) to 0.85 (Hanley, Tassé, Aman & Pace, 1998); (2) test-retest reliability (1 month interval): correlation was 0.75 for the average correlation among the 18 scale items; and (3) criterion validity: the FSS total scale score was consistently, but weakly, related to a number of parent and family outcomes, including personal well-being (correlation = 0.28), the integrity of the family unit (correlation = 0.18) and parent perceptions of child behaviour (correlation = 0.19), (Dunst et al., 1984). It has also been modified and tested in different cultures and settings (Mak & Ho, 2007; Park, Glidden & Shin, 2009).

Although the modified FSS did not show good criterion validity, the results could also suggest that families who need the most help are not getting enough support. Criterion validity of the original FSS in previous literature also showed weak correlations.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). The family support scales: reliability and validity. *Journal of Individual, Family and Community Wellness, 1*: 45-52.

Hanley, B., Tassé, M. J., Aman, M. G., & Pace, P. (1998). Psychometric properties of the Family Support Scale with Head Start families. *Journal of Child and Family Studies, 7*(1): 69-77.

Mak, W. W. S., & Ho, G. S. M. (2007). Caregiving perceptions of Chinese mothers of children with intellectual disability in Hong Kong. *Journal of Applied Research in Intellectual Disabilities, 20*: 145-156.

Park, S.-Y., Glidden, L. M., & Shin, J. Y. (2009). Structural and functional aspects of social support for mothers of children with and without cognitive delays in Vietnam. *Journal of Applied Research in Intellectual Disabilities, 23*: 38 - 51.

**APPENDIX I**

**Tables on differences between completers and non-completers for relevant outcome variables (**Number of Needs, Unmet Needs, Financial Problem, Employment Problem and Family Support Score)

Table I1: Significance level (p value) of differences in baseline characteristics between completers and non-completers of relevant outcome variables

| | p value for outcome variables | | | | |
|---|---|---|---|---|---|
| | Number of Needs | Number of Unmet needs | Financial Problem | Employment Problem | Family Support Score |
| Age category | 0.108 | 0.540 | 0.325 | 1.000 | 0.539 |
| Gender | 1.000 | 1.000 | 0.961 | 1.000 | 0.187 |
| Ethnicity | 0.306 | 0.154 | 0.053 | 0.139 | 0.860 |
| Primary caregiver | 1.000 | 1.000 | 1.000 | 1.000 | 0.544 |
| Marital status of primary caregiver | 0.649 | 0.591 | 0.527 | 0.328 | 0.510 |
| Primary caregiver's highest education | **0.008** | 0.119 | **0.001** | 0.132 | **0.019** |
| Income category of household | 0.092 | 0.313 | **0.032** | 0.115 | **0.001** |
| No. of children | 0.438 | 0.133 | 0.874 | 0.594 | 0.158 |
| No. of disabled children in the family | 0.213 | 0.189 | 1.000 | 1.000 | 0.421 |
| Caregiver has medical problem | 0.533 | 0.519 | 0.853 | 0.630 | 0.573 |

Table I2: Differences in caregiver's education level between completers and non-completers for the outcome Number of Needs

| | Completers (n = 292) | | Non-completers (n = 13) | | p value |
|---|---|---|---|---|---|
| | No. | % | No. | % | |
| **Primary caregiver's highest education** (mother/father or other caregiver) | | | | | 0.008 |
| No education | 4 | 1.4 | 0 | 0 | |
| Primary | 19 | 6.5 | 3 | 23.1 | |
| Lower secondary | 60 | 20.5 | 5 | 38.5 | |
| Upper secondary | 142 | 48.6 | 5 | 38.5 | |
| College/University | 66 | 22.6 | 0 | 0 | |
| Not answered | 1 | 0.3 | 0 | 0 | |

Table I3: Differences in caregiver's education level and household income level between completers and non-completers for the outcome Financial Problem

| | Completers (n = 283) | | Non-completers (n = 22) | | p value |
|---|---|---|---|---|---|
| | No. | % | No. | % | |
| **Primary caregiver's highest education** (mother/father or other caregiver) | | | | | 0.001 |
| No education | 4 | 1.4 | 0 | 0 | |
| Primary | 18 | 6.4 | 4 | 18.2 | |
| Lower secondary | 54 | 19.1 | 11 | 50.0 | |
| Upper secondary | 141 | 49.8 | 6 | 27.3 | |
| College/University | 65 | 23.0 | 1 | 4.5 | |
| Not answered | 1 | 0.4 | | | |
| **Income category of household** | | | | | 0.032 |
| <RM2000/month | 160 | 56.5 | 14 | 63.6 | |
| RM2000 – 3999/month | 31 | 11.0 | 3 | 13.6 | |
| ≥RM4000/month | 87 | 30.7 | 0 | 0 | |
| Not answered | 5 | 1.8 | 5 | 22.7 | |

Table I4: Differences in caregiver's education level and household income level between completers and non-completers for the outcome Family Support Score

| | Completers (n = 267) | | Non-completers (n = 38) | | p value |
|---|---|---|---|---|---|
| | No. | % | No. | % | |
| **Primary caregiver's highest education** (mother/father or other caregiver) | | | | | 0.019 |
| No education | 4 | 1.5 | 0 | 0 | |
| Primary | 20 | 7.5 | 2 | 5.3 | |
| Lower secondary | 48 | 18.0 | 17 | 44.7 | |
| Upper secondary | 131 | 49.1 | 16 | 42.1 | |
| College/University | 64 | 24.0 | 2 | 5.3 | |
| Not answered | | | 1 | 2.6 | |
| **Income category of household** | | | | | 0.001 |
| <RM2000/month | 145 | 54.3 | 29 | 76.3 | |
| RM2000 – 3999/month | 78 | 29.2 | 6 | 15.8 | |
| ≥RM4000/month | 37 | 13.9 | 0 | 0 | |
| Not answered | 7 | 2.6 | 3 | 7.9 | |

Table I5: Significance level (p value) of differences in ABILITIES Index score between completers and non-completers of relevant outcome variables

| | p value for outcome variables | | | | |
|---|---|---|---|---|---|
| | Number of Needs | Number of Unmet needs | Financial Problem | Employment Problem | Family Support Score |
| Overall | 0.139 | 0.746 | 0.194 | 0.325 | 0.990 |
| Hearing | 0.375 | **0.002** | 0.519 | 0.593 | **0.009** |
| Behaviour and social skills | 0.572 | 0.426 | 0.039 | 0.266 | 0.665 |
| Intellectual functioning | 0.842 | 0.808 | 0.521 | 0.661 | 0.930 |
| Limb functioning | 0.081 | 0.240 | 0.811 | 0.495 | 0.269 |
| Intentional communication | 0.360 | 0.208 | 0.641 | 0.215 | 0.562 |
| Tonicity | 0.101 | 0.520 | 0.475 | 0.248 | 0.632 |
| General health | 0.094 | 0.286 | 0.100 | 0.238 | 0.950 |
| Vision | 0.501 | 0.287 | 0.066 | 0.936 | 0.409 |
| Body structure | 0.138 | 0.528 | 0.250 | 0.613 | 0.843 |

Table I6: Comparison of ABILITIES Index score between completers and non-completers for outcome Number of Unmet Needs

| | Completers (n = 260) | | | Non-completers (n = 12) | | | p value |
|---|---|---|---|---|---|---|---|
| | Mean (SD) | Median | % with moderate, severe and profound problem | Mean (SD) | Median | % with moderate, severe and profound problem | |
| Overall | 42.6 (17.4) | 38.0 | | 39.5 (13.5) | 33.0 | | 0.746 |
| Hearing | 1.8 (1.5) | 1 | 15.3 | 3.3 (2.0) | 3.5 | 50.0 | 0.002 |

Table I7: Comparison of ABILITIES Index score between completers and non-completers for outcome Family Support Score

| | Completers (n = 267) | | | Non-completers (n = 38) | | | p value |
|---|---|---|---|---|---|---|---|
| | Mean (SD) | Median | % with moderate, severe and profound problem | Mean (SD) | Median | % with moderate, severe and profound problem | |
| Overall | 42.0 (17.2) | 36.0 | | 40.8 (15.3) | 36.5 | | 0.990 |
| Hearing | 1.7 (1.4) | 1 | 12.7 | 2.8 (2.1) | 1.5 | 21.1 | 0.009 |

**APPENDIX J**

## Findings on education support needs

Introduction:

Carers of children and youth with developmental disabilities and challenging behaviour expressed that one of the problems they faced was their child's exclusion from school (Wodehouse & McGill, 2009). According to the New Zealand Household Disability Survey 2002, around 90% of school aged children with physical disability were able to be enrolled at the school of their choice but around two-thirds of them had one or more problems joining in fully at school (Clark & MacArthur, 2008). A Thai study in a poor rural community identified only 55% of school-aged disabled children attended school (Pongprapai, Tayakkanonta, Chongsuvivatwong & Underwood, 1996).

Locating a preschool or day care centre was a problem for 57.6% of children with disabilities in a Malaysian study (Suriati et al., 2011) and approximately 50% in a Japanese study (Ueda et al., 2013), while it is less than 30% in other studies (Bailey Jr & Simeonsson, 1988; Farmer, Marien, Clark, Sherman & Selva, 2004).

Children with disabilities have different education needs based on their ages and severity of their disability. The decision on placement of children with disabilities in mainstream schools depends on the type and severity of disability the child has. In the case of children with autism spectrum disorders, the provision of additional basic educational support in mainstream primary education was associated with lower unmet educational support needs, but for children with cerebral palsy, mainstream school placement correlated with higher unmet need (Forsyth et al., 2010)

At times, the education placement of a disabled child depends not so much on psychological assessment but on social and political factors, such as whether a particular headmaster supports mainstream placement or whether the child's parents have a certain preference (Alderson & Goodey, 1998). Acquisition of functional skills, such as domestic and vocational skills is usually considered more relevant by parents (Westling, 1997). The lack of a welcoming mainstream environment might prompt doctors to recommend special education placement with the good intention of protecting the child, when inclusive education might actually be more beneficial to the child's learning (Alderson & Goodey, 1998).

The US Individuals with Disabilities Education Act (IDEA) sets a legal basis for providing education for all children in local schools, and requires public special education programmes to provide certain health-related services to children with disabilities (Perrin, 2002). It also provides for early intervention programmes for children from birth to 3 years, including specialized therapies. Thus, the child's health care needs are met within the context of the education system. However, Malaysia does not have such provisions in its Ministry of Education policies.

Results:

Among caregivers of children aged 0 – 3 years, 83.0% (95% CI 69.2, 91.4) of them had heard of early intervention (table J1). Around half of the caregivers of children aged 4 – 12 years and who were not bedridden reported having problems finding a suitable pre-school or primary school for their child. A higher percentage of caregivers had a big problem finding a pre-school for their child (31.8%, 95% CI 18.3, 49.2) compared to finding a primary school (22.2%, 95% CI 16.2, 29.7).

Discussion:

Caregivers reported problems finding suitable schools for their child, with pre-school being a bigger problem than primary school. The most frequently cited reasons for this problem were that caregivers did not know what type of education was suitable for their child and did not know the types of schools or classes available for special needs children. This finding shows that education for special needs children in Malaysia remains very elusive to parents.

A lack of parental involvement in their child's education plan stems from parents' lack of knowledge about their child's education needs and learning potential. Parents are not confident to make educational decisions, preferring to leave it to the teachers or health professionals whom they perceive would know their child's requirements better (Siti Hasnah & Zalizan, 2012).

Table J1: Distribution of caregivers who had heard of early intervention and who had problems finding a suitable school for their child with disability

| | Percentage | 95% CI | | Unweighted count |
|---|---|---|---|---|
| | | Lower | Upper | |
| **Heard of early intervention (Child aged 0 – 3 years)** | | | | |
| Yes | 83.0 | 69.2 | 91.4 | 25 |
| No | 17.0 | 8.6 | 30.8 | 8 |
| Total | | | | 33 |
| **Problems finding pre-school (Child not bedridden aged 4 – 6 years)** | | | | |
| No problem | 30.9 | 17.6 | 48.4 | 16 |
| Small problem | 27.5 | 14.8 | 45.4 | 13 |
| Big problem | 31.8 | 18.3 | 49.2 | 17 |
| Not relevant | 9.7 | 3.1 | 26.7 | 4 |
| Total | | | | 50 |
| **Problems finding primary school (Child not bedridden aged 7 – 12 years)** | | | | |
| No problem | 40.1 | 32.4 | 48.3 | 73 |
| Small problem | 28.6 | 21.7 | 36.6 | 50 |
| Big problem | 22.2 | 16.2 | 29.7 | 42 |
| Not relevant | 4.9 | 2.4 | 10.0 | 9 |
| Not answered | 4.1 | 1.9 | 8.9 | 8 |
| Total | | | | 182 |
| **Problems finding school (Child not bedridden aged 4 – 12 years)** | | | | |
| Yes | 52.3 | 44.9 | 59.5 | 122 |
| No | 38.5 | 31.7 | 45.8 | 89 |
| Not relevant | 5.8 | 3.2 | 10.3 | 13 |
| Not answered | 3.4 | 1.6 | 7.3 | 8 |
| Total | | | | 232 |
| **Problems faced finding school (n = 122)** | | | | |
| Lack of suitable facilities in school | 3.2 | 2.0 | 5.3 | 9 |
| Lack of suitable teachers | 17.9 | 11.3 | 27.3 | 20 |
| Do not know what type of education is suitable | 31.6 | 22.8 | 41.9 | 33 |
| Do not know what type of schools/classes available | 20.1 | 13.1 | 29.4 | 25 |
| Others | 18.3 | 11.7 | 27.5 | 23 |

However, most doctors are not able to identify correctly children with learning disabilities. Assessment of learning difficulties is not taught in the standard medical curriculum. Under the Literacy and Numeracy Screening (LINUS) programme, parents of students suspected to have learning disability are asked to refer the child to the health clinic for confirmation of their special learning needs. A medical officer serving in the health clinic will not have the expertise to perform this kind of assessment if he/she has not been sufficiently trained to do so. Even general paediatricians lack the skills to adequately assess milder learning disabilities such as dyslexia, dyspraxia and high functioning autism. Only those who have undergone training to become developmental paediatricians or community paediatricians will have the knowledge to confidently diagnose learning disabilities but currently, there is a lack of such expertise. There is also a serious lack of educational psychologists and other trained professionals in both the Ministry of Health (MOH) and Ministry of Education (MOE) to aid in the assessment of learning disabilities.

Early intervention programmes and inclusive education is not widely implemented in Malaysia. Most Malaysian parents send their children to pre-schools (nurseries or kindergartens) which are privately owned, and where the priority is usually on academic achievement. There are only a small number of pre-schools with integrated special education programmes under the MOE. Early intervention centres in Malaysia are currently not yet that well established and most that are available are run by NGOs.

In Turkey, the lack of support for children with special health care needs to study in mainstream settings has caused a rapid increase in the number of private special education schools or therapy centres, which normally emphasize on financial gain (Uslu & Girgin, 2009). A monthly social welfare payment is made only for the child that attends a special school and not a mainstream school, resulting in parents having an incentive to send their child to special school, further discouraging inclusive education.

Public funded intervention centres for children with learning disabilities incorporating specialized therapies would be a more affordable option to low income families. Ideally, these intervention centres should come under the supervision of the MOE and not the MOH or Department of Social Welfare because we should avoid seeing children with learning difficulties as having a medical problem or as a person that needs charity, but rather as a person who has special education needs.

The MOE launched the Leaving No Child Behind; Individual Education Plan (IEP) for Children with Special Needs Project in 2010. Implementation of the policy however, has been slow and problematic. Teachers involved in the IEP process reported lack of knowledge and skills on how to develop a good IEP despite having undergone some training in special education. Lack of support from school management, lack of involvement from parents, and the problem that preparation of an IEP involves a lot of paper work and is time consuming, were encountered (Siti Hasnah & Zalizan, 2012).

Lack of guidance in developing an IEP means teachers may heavily rely on health professionals' opinions on the child. Unfortunately, health professionals are even more lacking in the competence to assess and recommend strategies related to the education of the child. In the Malaysian disability certification form, doctors are required to suggest the type of education placement for the child, which then becomes a reference for education authorities. It is unfair to both the child and the intended class or school because it is beyond the professional remit of doctors to be highly knowledgeable about education provision in different settings as doctors do not observe daily classroom practice in local mainstream, integrated or special schools.

Perhaps doctors who are not developmental paediatricians should be confined to commenting on any special medical factors that need to be taken into account in the holistic assessment of the child for education placement. Clinical assessment of a child with learning difficulties should be clearly distinguished from educational assessment. Nevertheless, doctors can advocate for education that is suitable for the child as their opinions carry a lot of weight among local education authorities, parents and the general public.

Conclusion:

Caregivers in Malaysia faced problems finding suitable education for their child with disability and the MOE's IEP for Children with Special Needs project still faces a lot of implementation problems. Children with disabilities have a right to education just like their peers, and there needs to be more effort to provide quality inclusive education or special education, according to the child's education needs.

References:


Alderson, P., & Goodey, C. (1998). Doctors, ethics and special education. *Journal of Medical Ethics, 24*(1): 49-55.

Bailey Jr, D. B., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. *The Journal of Special Education, 22*(1): 117-127.

Clark, P., & MacArthur, J. (2008). Children with physical disability: Gaps in service provision, problems joining in. *Journal of Paediatrics and Child Health, 44*: 455 - 458.

Farmer, J. E., Marien, W. E., Clark, M. J., Sherman, A., & Selva, T. J. (2004). Primary care supports for children with chronic health conditions: Identifying and predicting unmet family needs. *Journal of Paediatric Psychology, 29*(5): 355 - 367.

Forsyth, R., McNally, R., James, P., Crossland, K., Woolley, M., & Colver, A. (2010). Variation at local government level in the support for families of severely disabled children and the factors that affect it. *Dev Med Child Neurol, 52*(11): e259-266. doi: 10.1111/j.1469-8749.2010.03778.x

Hendriks, A. H., Moor, J. M. D., Oud, J. H., & Franken, W. M. (2000). Service needs of parents with motor or multiply disabled children in Dutch therapeutic toddler classes. *Clinical Rehabilitation, 14*(5): 506-517.

Perrin, J. M. (2002). Health services research for children wtih disabilities. *The Milbank Quarterly, 80*(2): 303 - 324.

Pongprapai, S., Tayakkanonta, K., Chongsuvivatwong, V., & Underwood, P. (1996). A study on disabled children in a rural community in southern Thailand. *Disability And Rehabilitation, 18*(1): 42-46.

Siti Hasnah, B., & Zalizan, M. J. (2012). The IEP: Are Malaysian teachers ready? *Procedia Social and Behavioural Sciences, 47*(Cyprus International Conference on Educational Research (CY-ICER-2012)): 1341-1347.

Suriati, S., Zainiyah, S. S., Lye, M., & Norlijah, O. (2011). Assessing the unmet needs among caregivers of children with disabilities at the community-based rehabilitation centres in Selangor. *Malaysian Journal of Public Health Medicine, 11*(2): 32 - 40.

Ueda, K., Bailey Jr, D. B., Yonemoto, N., Kajikawa, K., Nishigami, Y., Narisawa, S., . . . Kodama, K. (2013). Validity and reliability of the Japanese version of the Family Needs Survey. *Research in Developmental Disabilities, 34*(10): 3596-3606.

Uslu, M., & Girgin, C. (2009). Determining and evaluating the needed psychological support and education to families of children with special health care needs. *Procedia Social and Behavioural Sciences*(World Conference on Educational Sciences 2009): 1366 - 1371. doi: 10.1016/j.sbspro.2009.01.241

Westling, D. L. (1997). What parents of young children with mental disabilities want: The views of one community. *Focus on Autism & Other Developmental Disabilities, 12*(2): 67.

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it from being helpful? *Journal of Intellectual Disability Research, 53*(7): 644 - 653.

**APPENDIX K**

## Tables on distribution of needs and unmet needs by type of service/assistive device

Table K1: Distribution of needs and unmet needs for **specialist doctor** services by disability category

| | Learning % (95% CI) | Unweighted count | Multiple % (95% CI) | Unweighted count | Others % (95% CI) | Unweighted count |
|---|---|---|---|---|---|---|
| Need | 62.7 (53.9, 70.7) | 79 | 89.3 (80.6, 94.4) | 75 | 70.9 (61.6, 78.7) | 66 |
| **Unmet need** | 40.5 (30.2, 51.8) | 32 | 30.7 (21.2, 42.1) | 23 | 35.3 (24.6, 48.1) | 23 |
| Received partially | 29.1 (20.1, 40.2) | 23 | 25.3 (16.7, 36.5) | 19 | 31.3 (21.0, 43.8) | 20 |
| Did not receive at all | 11.4 (6.0, 20.6) | 9 | 5.3 (2.0, 13.5) | 4 | 4.2 (1.3, 12.5) | 3 |

Table K2: Distribution of needs and unmet needs for **dental services** by disability category

| | Learning % (95% CI) | Unweighted count | Multiple % (95% CI) | Unweighted count | Others % (95% CI) | Unweighted count |
|---|---|---|---|---|---|---|
| Need | 48.4 (39.8, 57.2) | 61 | 64.3 (53.4, 73.9) | 54 | 41.0 (31.6, 51.2) | 39 |
| **Unmet need** | 63.9 (51.0, 75.1) | 39 | 44.4 (31.7, 58.0) | 24 | 61.2 (46.8, 73.9) | 23 |
| Received partially | 31.1 (20.7, 44.0) | 19 | 29.6 (18.9, 43.3) | 16 | 33.0 (20.6, 48.3) | 12 |
| Did not receive at all | 32.8 (22.1, 45.7) | 20 | 14.8 (7.5, 27.2) | 8 | 28.2 (15.9, 44.9) | 11 |

Table K3: Distribution of needs and unmet needs for **dietary or nutritional advice** by disability category

| | Learning % (95% CI) | Unweighted count | Multiple % (95% CI) | Unweighted count | Others % (95% CI) | Unweighted count |
|---|---|---|---|---|---|---|
| Need | 28.6 (21.3, 37.1) | 36 | 51.2 (40.5, 61.8) | 43 | 22.5 (15.0, 32.3) | 21 |
| **Unmet need** | 69.4 (52.3, 82.5) | 25 | 55.8 (40.5, 70.1) | 24 | 44.1 (23.7, 66.7) | 9 |
| Received partially | 33.3 (19.7, 50.5) | 12 | 23.3 (12.8, 38.5) | 10 | 19.2 (7.3, 41.7) | 4 |
| Did not receive at all | 36.1 (21.9, 53.2) | 13 | 32.6 (20.1, 48.1) | 14 | 24.9 (10.5, 48.2) | 5 |

Table K4: Distribution of needs and unmet needs for **psychological services** by disability category

| | Learning % (95% CI) | Unweighted count | Multiple % (95% CI) | Unweighted count | Others % (95% CI) | Unweighted count |
|---|---|---|---|---|---|---|
| Need | 31.0 (23.4, 39.6) | 39 | 19.0 (12.0, 29.0) | 16 | 7.3 (3.5, 14.6) | 7 |
| **Unmet need** | 64.1 (47.6, 77.9) | 25 | 56.3 (31.2, 78.5) | 9 | 58.9 (26.5, 85.1) | 4 |
| Received partially | 30.8 (18.0, 47.3) | 12 | 31.3 (13.0, 58.1) | 5 | 13.6 (1.5, 61.6) | 1 |
| Did not receive at all | 33.3 (20.1, 49.9) | 13 | 25.0 (9.2, 52.4) | 4 | 45.3 (17.7, 76.1) | 3 |

Table K5: Distribution of needs and unmet needs for **physiotherapy** by disability category

| | Physical % (95% CI) | Unweighted count | Multiple % (95% CI) | Unweighted count |
|---|---|---|---|---|
| Need | 55.3 (39.2, 70.3) | 21 | 82.1 (72.4, 89.0) | 69 |
| **Unmet need** | 47.6 (27.2, 68.8) | 10 | 34.8 (24.3, 46.9) | 24 |
| Received partially | 19.0 (7.1, 42.1) | 4 | 26.1 (16.9, 37.9) | 18 |
| Did not receive at all | 28.6 (13.0, 51.6) | 6 | 8.7 (3.9, 18.3) | 6 |

Table K6: Distribution of needs and unmet needs for **mobility aids** by disability category

| | Physical | | Multiple | |
|---|---|---|---|---|
| | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count |
| Need | 34.2 (20.8, 50.7) | 13 | 63.1 (52.2, 72.8) | 53 |
| **Unmet need** | 69.2 (39.2, 88.7) | 9 | 52.8 (39.1, 66.1) | 28 |
| Received partially | 7.7 (0.9, 42.0) | 1 | 13.2 (6.3, 25.6) | 7 |
| Did not receive at all | 61.5 (32.8, 84.0) | 8 | 39.6 (27.1, 53.6) | 21 |

Table K7: Distribution of needs and unmet needs for **occupational therapy** by disability category

| | Learning | | Physical | | Multiple | |
|---|---|---|---|---|---|---|
| | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count |
| Need | 57.9 (49.1, 66.3) | 73 | 52.6 (36.8, 68.0) | 20 | 81.0 (71.0, 88.0) | 68 |
| **Unmet need** | 46.6 (35.3, 58.2) | 34 | 45.0 (24.8, 67.0) | 9 | 36.8 (26.1, 49.0) | 25 |
| Received partially | 27.4 (18.3, 38.9) | 20 | 15.0 (4.7, 38.6) | 3 | 25.0 (16.0, 36.8) | 17 |
| Did not receive at all | 19.2 (11.6, 30.0) | 14 | 30.0 (13.8, 53.5) | 6 | 11.8 (5.9, 22.0) | 8 |

Table K8: Distribution of needs and unmet needs for **speech therapy** by disability category

| | Learning | | Hearing or speech | | Non-hearing or speech† | |
|---|---|---|---|---|---|---|
| | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count |
| Need | 61.1 (52.3, 69.3) | 77 | 70.0 (53.7, 82.5) | 28 | 41.1 (34.2, 48.3) | 57 |
| **Unmet need** | 61.0 (49.6, 71.4) | 47 | 32.0 (17.7, 50.8) | 9 | 49.9 (35.8, 62.4) | 28 |
| Received partially | 37.7 (27.5, 49.1) | 29 | 17.7 (8.0, 34.9) | 5 | 19.1 (10.7, 31.7) | 11 |
| Did not receive at all | 23.4 (15.2, 34.3) | 18 | 14.3 (5.3, 33.0) | 4 | 29.0 (19.0, 43.7) | 17 |

†Children with physical, visual or multiple disabilities who may have hearing or speech difficulties

Table K9: Distribution of needs and unmet needs for **communication aids** by disability category

| | Learning | | Hearing or speech disability | | Non-hearing or speech disability† | |
|---|---|---|---|---|---|---|
| | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count | % (95% CI) | Unweighted count |
| Need | 34.1 (26.3, 42.9) | 43 | 37.6 (24.1, 53.3) | 15 | 28.5 (21.8, 36.3) | 39 |
| **Unmet need** | 83.7 (69.2, 92.2) | 36 | 53.3 (28.3, 76.8) | 8 | 72.2 (56.5, 83.8) | 28 |
| Received partially | 18.6 (9.4, 33.4) | 8 | 20.0 (6.2, 48.5) | 3 | 12.6 (5.3, 27.2) | 5 |
| Did not receive at all | 65.1 (49.5, 78.0) | 28 | 33.3 (14.0, 60.7) | 5 | 59.5 (43.6, 73.7) | 23 |

†Children with physical, vision or multiple disabilities who may have hearing or speech difficulties

Table K10: Distribution of needs and unmet needs for **vision related services** by disability category

| | Visual disability % (95% CI) | Unweighted count | Non-visual disability† % (95% CI) | Unweighted count |
|---|---|---|---|---|
| Need | 94.1 (66.4, 99.2) | 16 | 25.4 (20.2, 31.4) | 81 |
| **Unmet need** | 50.0 (26.4, 73.6) | 8 | 48.4 (35.7, 61.3) | 36 |
| Received partially | 37.5 (17.2, 63.4) | 6 | 32.5 (21.4, 46.1) | 22 |
| Did not receive at all | 12.5 (2.9, 40.2) | 2 | 15.9 (8.6, 27.6) | 14 |

†Children with learning, physical, hearing or multiple disabilities who may have vision problems
Note: Example of vision related services is optometry assessment

Table K11: Distribution of needs and unmet needs for **vision aids** by disability category

| | Visual disability % (95% CI) | Unweighted count | Non-visual disability† % (95% CI) | Unweighted count |
|---|---|---|---|---|
| Need | 70.6 (44.9, 87.6) | 12 | 14.6 (10.5, 19.9) | 45 |
| **Unmet need** | 66.7 (35.7, 87.7) | 8 | 50.2 (33.3, 67.0) | 26 |
| Received partially | 8.3 (1.0, 44.8) | 1 | 10.3 (3.3, 28.1) | 4 |
| Did not receive at | 58.3 (29.1, 82.7) | 7 | 39.9 (25.0, 57.0) | 22 |

| | | | | |
|---|---|---|---|---|
| all | | | | |

†Children with learning, physical, hearing or multiple disabilities who may have vision problems

Table K12: Distribution of needs and unmet needs for **hearing related services** by disability category

| | Hearing disability % (95% CI) | Unweighted count | Non-hearing disability† % (95% CI) | Unweighted count |
|---|---|---|---|---|
| Need | 94.7 (80.9, 98.7) | 36 | 23.4 (18.2, 29.6) | 66 |
| **Unmet need** | 22.2 (11.3, 39.0) | 8 | 42.1 (29.0, 56.4) | 23 |
| Received partially | 13.9 (5.8, 29.8) | 5 | 27.2 (16.2, 41.9) | 15 |
| Did not receive at all | 8.3 (2.6, 23.4) | 3 | 14.9 (7.1, 28.8) | 8 |

†Children with learning, physical, visual or multiple disabilities who may have hearing difficulties

Note: Example of hearing related services is audiometry assessment

Table K13: Distribution of needs and unmet needs for **hearing aids** by disability category

| | Hearing disability % (95% CI) | Unweighted count | Non-hearing disability† % (95% CI) | Unweighted count |
|---|---|---|---|---|
| Need | 89.5 (74.8, 96.1) | 34 | 3.4 (1.7, 6.5) | 12 |
| **Unmet need** | 17.6 (7.9, 35.0) | 6 | 61.6 (24.0, 89.1) | 7 |
| Received partially | 11.8 (4.3, 28.4) | 4 | 22.7 (3.5, 70.3) | 2 |
| Did not receive at all | 5.9 (1.4, 21.8) | 2 | 38.9 (11.1, 76.4) | 5 |

†Children with learning, physical, visual or multiple disabilities who may have hearing difficulties

**APPENDIX L**

## Results of utilization of rehabilitation services by children who were bedridden and children with learning disability with/without behavioural problem

Table L1: Frequency of therapy, number of facilities and type of facility where children who were bedridden received rehabilitation services

| | Percentage | 95% CI Lower | Upper | Unweighted count |
|---|---|---|---|---|
| **Frequency of therapy** | | | | |
| Once every 4 - 6 months | 4.8 | 1.2 | 17.6 | 2 |
| Once every 2 - 3 months | 2.4 | 0.3 | 15.5 | 1 |
| Once a month | 30.6 | 18.6 | 46.0 | 13 |
| More than once a month | 62.2 | 46.7 | 75.5 | 26 |
| Total | | | | 42 |
| **No. of facilities** | | | | |
| 1 | 45.0 | 30.7 | 60.2 | 19 |
| 2 | 38.4 | 25.0 | 53.9 | 16 |
| >2 | 16.6 | 8.0 | 31.2 | 7 |
| Total | | | | 42 |
| **Type of facility** | | | | |
| Government hospital | 73.6 | 58.2 | 84.8 | 31 |
| Government health clinic | 21.4 | 11.4 | 36.5 | 9 |
| PDK | 43.0 | 28.9 | 58.4 | 18 |
| Private hospital/ therapist | 9.4 | 3.5 | 22.8 | 4 |
| NGO centre | 28.6 | 16.9 | 44.2 | 12 |

Notes:

a) Percentage was calculated for those who answered they received therapy in the past one year

b) One child could receive therapy from more than one facility

Table L2: Receipt of rehabilitation services among children with learning disability with and without behavioural problem (n = 108)

| | With behaviour problem | | | Without behaviour problem | | |
|---|---|---|---|---|---|---|
| **Receive therapy** | % | 95% CI | Unweighted count | % | 95% CI | Unweighted count |
| Yes | 66.7 | 52.7, 78.2 | 34 | 54.4 | 41.3, 66.8 | 31 |
| No | 25.5 | 15.3, 39.2 | 13 | 26.3 | 16.5, 39.3 | 15 |
| Not relevant* | 3.9 | 1.0, 14.5 | 2 | 15.8 | 8.4, 27.8 | 9 |
| Not answered | 3.9 | 1.0, 14.5 | 2 | 3.5 | 0.9, 13.1 | 2 |
| Total | | | 51 | | | 57 |

*Not relevant – children with a learning disability whom caregivers felt that they do not require therapy in the past one year

A higher percentage of children with learning disability and co-existing behavioural problem received therapy more than once a month and received therapy in two or more facilities (table L3). In addition, a higher percentage of these children utilized services from the private sector and NGOs compared to children with learning disability and without co-existing behavioural problem. Caregivers needed more help handling the child's behaviour and because child psychology services in the public sector were not sufficient, caregivers had to rely on private or charity funded services.

Table L3: Frequency of therapy, number of facilities and type of facility where children with learning disability with and without behavioural problem received rehabilitation services

| | With behavioural problem | | | Without behavioural problem | | |
|---|---|---|---|---|---|---|
| | % | 95% CI | Unweighted count | % | 95% CI | Unweighted count |
| **Frequency of therapy** | | | | | | |
| Once every 4 - 6 months | 2.9 | 0.4, 18.6 | 1 | 25.8 | 13.3, 44.0 | 8 |
| Once every 2 - 3 months | 8.8 | 2.8, 24.4 | 3 | 9.7 | 3.1, 26.4 | 3 |
| Once a month | 32.4 | 18.7, 49.8 | 11 | 25.8 | 13.3, 44.0 | 8 |
| More than once a month | 55.9 | 38.9, 71.6 | 19 | 38.7 | 23.3, 56.8 | 12 |
| Total | | | 34 | | | 31 |
| **No. of facilities** | | | | | | |
| 1 | 50.0 | 33.6, 66.4 | 17 | 58.1 | 40.2, 74.1 | 18 |
| 2 | 35.3 | 21.1, 52.7 | 12 | 32.3 | 18.2, 50.6 | 10 |
| >2 | 14.7 | 6.2, 31.1 | 5 | 9.7 | 3.1, 26.4 | 3 |
| Total | | | 34 | | | 31 |
| **Type of facility** | | | | | | |
| Government hospital | 73.5 | 56.2, 85.8 | 25 | 71.0 | 52.7, 84.3 | 22 |
| Government health clinic | 17.6 | 8.1, 34.4 | 6 | 35.5 | 20.7, 53.7 | 11 |
| PDK | 20.6 | 10.0, 37.6 | 7 | 29.0 | 15.7, 47.3 | 9 |
| Private hospital/ therapist | 29.4 | 16.5, 46.8 | 10 | 3.2 | 0.4, 20.1 | 1 |
| NGO | 29.4 | 16.5, 46.8 | 10 | 12.9 | 4.9, 30.1 | 4 |

Notes:

a) Percentage was calculated for those who answered they received therapy in the past one year
b) One child could receive therapy from more than one facility